

BLAME IT ON THE CHEMO

How do humor and
optimism help this teen
face challenges?

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By Hill Harper



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The chemo made her do it. Originae Brown has decided that this is one time in her life when she has a foolproof excuse for any personal shortcoming. The vivacious teen claims she can blame almost anything on the chemotherapy she receives as part of her treatment for the bone cancer osteosarcoma.

"If I forget something, I can just say, 'Oh, it's that chemo—it makes me forget things,'" she says, flashing a mischievous smile. In fact, while undergoing treatment at St. Jude Children's Research Hospital, the 15-year-old is writing a rap song titled "Blame It on the Chemo." It's one way she can thumb her nose at the disease that has temporarily interrupted her life. Originae doesn't complain about her situation; she's confident that a positive attitude, steadfast faith and excellent medical care will carry her through.

"I don't want any sympathy or pity, because I know I'm going to come out of here 100 percent fine," Originae says.



"I've learned that life is bigger than the small things," Originae says. "I've learned not to take life for granted. And I've learned that you should never give up. Just smile and keep going."

Blame It on the Chemo

Originae Brown takes challenges in stride. Hair loss. Major surgery. Even the chemotherapy that makes her so sick. No matter what happens, this high-spirited teen keeps smiling.

BY ELIZABETH JANE WALKER

Two simple questions

Winston Churchill once defined attitude as "a little thing that makes a big difference." For Originae, attitude is not a small thing—it's the only thing. Since arriving at St. Jude in April of 2012, the teenager has delighted caregivers and fellow patients with her optimism and sunny demeanor.

Originae's journey to St. Jude began in the seventh grade, when the energetic young athlete experienced pain in her right leg during volleyball, softball and cheerleading activities.

"She was misdiagnosed for more than a year by our local doctors," says Originae's mom, Shandell Brown. "They treated it as tendonitis, telling us to apply ice or warm compresses and to elevate her leg. Nothing showed up on MRIs or X-rays."

Finally, in the spring of her eighth-grade year, Originae tumbled onto the floor in excruciating pain. This time, tests revealed a mass in

her right knee. The doctor suspected osteosarcoma, the most common type of bone cancer in children and adolescents.

Originae had only two questions for the physician: "Is it curable?" and "Am I going to die?"

"It is curable," he replied. "One of the best hospitals for pediatric cancer is St. Jude. We're going to send you there."

Originae immediately exuded a sense of peace and allayed the fears of her family and friends. "Because I was calm, the rest of my family became calm about it," she explains.

The sprint begins

Originae and her parents quickly adjusted to life at St. Jude.

"I had never been to a facility where everyone was so friendly and open and compassionate—from the receptionists to security to the housing staff," Shandell says. "They made us feel like we had a home away from home. We didn't even



Originae enjoys expressing herself through rap. "There's a message in all of my songs," she says. "I want to use music in a positive way to reach other kids." To hear one of Originae's songs, visit www.stjude.org/Promise.



Originae says she aspires to a medical career because of Wayne Furman, MD (top photo). “Dr. Furman inspires me, and I want to be like him,” she explains. At the hospital’s Halloween festivities, Originae dressed as Furman, affixing a “Furmanator” nametag to her lab coat and emblazoning his favorite quote on her back: “This is not a sprint; it’s a marathon.”

have to stress about the cost of housing, food, airfare or medical bills. I immediately realized that we had made the best decision to have our daughter’s treatment here.”

At St. Jude, Originae enrolled in a clinical trial that combined standard chemotherapy with the addition of a novel drug called bevacizumab. This antibody stops tumor growth by preventing the VEGF protein from stimulating new blood vessel formation in the tumor.

Originae learned that this treatment to shrink the tumor would be followed by a limb-sparing operation and additional chemotherapy.

Her St. Jude oncologist, Wayne Furman, MD, warned the teen that the journey would be long.

“This is not a sprint; it’s a marathon,” he told her.

“No, not for me,” she replied. “I’m going to sprint through this cancer treatment.”

The teen approached her

treatment with the same zeal she had previously exhibited on the volleyball court. “I always tell my chemotherapy, ‘You’re not going to get the best of me,’” she says.

When her hair began to thin, Originae washed out the remaining strands. “I never thought I’d like a bald head, but I’m fine with it,” she says.

Every morning, regardless of her nausea or exhaustion, Originae spends a couple of hours building the perfect outfit, complete with matching nail polish and accessories. In cool weather, she may add a wig to her ensemble.

Shandell has often begged her daughter to put on a T-shirt and jeans and abandon her beauty rituals. Originae refuses to consider that option.

“Every day, I’m going to put a smile on my face, and I’m going to look my best,” she explains. “I can get through this as long as I’m strong and I have a good attitude. If you don’t have a good attitude, it’s not going to be as easy.”

Temporary setbacks

In August of 2012, Originae underwent a limb-sparing operation, during which surgeon Michael Neel, MD, removed the diseased bone and replaced it with a prosthetic bone. Through the following months, Originae worked with staff in St. Jude Rehabilitation Services to regain the use of her leg while undergoing additional chemotherapy treatments.

In November, doctors allowed her to return home to Louisiana for Thanksgiving. A happy homecoming transformed into a nightmare when she developed a life-threatening infection in her leg. She was rushed by ambulance

to Memphis, where she underwent surgery to remove the infection.

Originae also became extremely sensitive to the chemotherapy drug methotrexate, which causes mucositis, a painful inflammation of the membranes lining the entire gastrointestinal tract. Her treatment was delayed several times because of hospitalizations due to this complication.

“In December, I spent three weeks in the hospital because of mucositis,” she says. “It was horrible. I couldn’t hold down food, and I was burned from the top to the bottom. My fingers and toes even burned from the chemo.”

Contagious optimism

Incredibly, Originae kept on smiling—even when the mucositis prevented her from speaking.

For Christmas, she gave specific instructions to her family: “I don’t want anything; I have everything I could possibly want,” she told them. “Just make a donation to St. Jude.”

As time passed, Originae’s clinical team marveled at the teen’s perpetual buoyancy and her profound sense of gratitude.

“Initially, I must admit that I thought she was in denial,” Furman says. “But then I realized it’s just the way she is—with her bubbly, positive attitude. Not only does she continue to smile, but when people come see her, they usually walk away smiling, too.”

“You can’t help but love her,” adds Margaret Edwards, RN, of Pharmaceutical Sciences. “A positive attitude goes a long way when you’re fighting a disease like cancer.”

Occasionally, Originae confused her medical team by

cheerfully reporting a high pain level—perhaps an 8 out of 10.

“Dr. Furman once said, ‘If that’s an 8, then what does a zero look like?’” Originae recalls. “One day I came in the clinic with no pain at all, and I was jumping around and full of energy. He said, ‘Well, now I know what a zero looks like.’”

Pass it on

Originae has become a self-appointed happiness ambassador.

“It’s my job to make people happy around here,” she says with a grin. “If I see someone who’s down, I’m definitely going to talk to them.”

The teen has become a resource for staff, who understand the power of a peer.

“Originae is the life of the party, but she’s also humble and thoughtful and reflective,” says Jessica Boles of Child Life.

“When she enters a room, everybody’s her friend. She has never met a stranger.”

Boles first encountered Originae at an event called “Ask the Teens,” in which patients offered their suggestions and observations about the hospital’s Child Life program. In the following months, Originae participated in “Real Talk” groups, in which teens share their feelings and insights with chaplains and Child Life specialists. Boles observed that other teens were drawn to Originae, who offered sound advice about topics ranging from dealing with

nausea to navigating the social scene.

“Sometimes, patients who have been down about their diagnoses will tell me that they ran into Originae and that she talked with them,” says Mistie Parker, RN, of the Ambulatory Care Unit. “I don’t know what she tells them, but she makes them feel better.”

Originae says she has become stronger and more confident during her journey through cancer. She has also learned a few lessons: “I’ve learned that life is bigger than the small things,” she says. “I’ve learned not to take life for granted. And I’ve learned that you should never give up. Just smile and keep going.”

And when she runs into a problem or challenge? That’s easy: Blame it on the chemo. ●

Osteosarcoma

400 children and adolescents in the U.S. are diagnosed with this type of bone cancer each year.

75% 5-year survival rate for patients whose disease has not spread.

95% of patients with localized disease can be considered for surgery to replace the diseased bone with a prosthesis or graft.

Clinical trials

For information about the latest St. Jude clinical trials for osteosarcoma and other pediatric cancers, visit www.stjude.org/clinicaltrials.



Putting Quality *into* Life

The St. Jude Quality of Life and Palliative Care Division strives to become an international resource for improving the quality of life for patients and their families.

BY MIKE O'KELLY



Children often enjoy ranking their favorite dance moves, athletic achievements or artistic performances on scales from 1 to 10, but those numerals can have a different meaning for some patients undergoing treatment at St. Jude Children's Research Hospital. Their rankings are part of an assessment tool developed by the hospital's Quality of Life specialists. This tool helps St. Jude staff identify and manage issues affecting children undergoing treatment.

Through their initial assessment and follow-up visits, these specially trained employees work with a patient's primary care team and family to incorporate other disciplines to address the child's range of needs.

"If we notice any distress during the assessment, then we brainstorm and talk with the patient's family about how we can best help them," says Angela Snyder, NP, who along with Karen Williams,

Two-year-old Jocelyn Woodruff and her mom, Joanna, visit with Deena Levine, MD, and Justin Baker, MD, during a Quality of Life consultation.

PETER BARTA

"All of these efforts combine to help kids have good days. Our goal is to become a worldwide resource in finding the best ways to make that happen."

NP, serves as one of two advanced practice nurses known as Quality of Life specialists.

This interaction with patients and families is an integral part of a St. Jude effort to improve the quality of life for patients and their family members.

Integrating care

Justin Baker, MD, and his colleagues provide quality-of-life and palliative care services early in a child's treatment journey.

"We focus on communicating, building relationships and continuing those relationships across various care environments," says Baker, chief of the hospital's Quality of Life and Palliative Care division. "We've been able to create a model where palliative care and oncology are working hand-in-hand much earlier."

Through clinical trials, consult services and cross-coordination of care, Baker's team ensures that communication lines include the child's primary care team as well as social workers, chaplains, child life specialists and other staff in supportive roles.

The St. Jude program is one of only a few in the nation that provides services in a variety of health care settings: intensive care, inpatient, outpatient, patient

housing and patients' homes.

Baker's team works with clinical areas across campus to identify palliative care champions from each service to further that integration of care.

The division has also branched out to establish roots in the Memphis community, collaborating with local partners to form the Quality of Life for All Kids Program to serve the needs of children who are suffering from complex chronic conditions.

"Because we are a patient and family-centered care hospital, it's important for us to keep families and their illness experiences in the forefront of our minds," Williams says. "We work hard to stay involved with the families."

Families at the center

Baker stresses the importance of involving families in every aspect of the division's work—from strategic planning to the Quality of Life consult service.

Team members have partnered with bereaved parents to obtain recommendations, which have included the addition of a professional to provide support for surviving family members and hospital staff after the loss of a child. As the hospital's new bereavement coordinator, Nancy Noyes personally relates to family

members grieving the loss of a child. Her son, Matt, a former St. Jude patient, died in 2008 after a six-year battle with a brain tumor.

“It’s amazing to be back at St. Jude as a health care professional interacting with people who played such a big part in Matt’s life,” says Noyes, who brings to her position an extensive background in pediatric oncology, research, and child and adolescent psychiatry.

“Everyone grieves differently,” Noyes continues, “and I feel that as a bereaved parent, I’ll have a unique connection to families.”

A steering committee consisting of parents and St. Jude staff will train bereaved parents to serve as mentors and educators for other families and hospital staff. This committee will also help plan and develop the annual St. Jude Day of Remembrance event.

Furthering education

In addition to involving families, the division offers educational seminars and activities

for hospital employees.

St. Jude also partners with two other health care institutions to provide a fellowship program for future hospice and palliative medicine physicians.

Trainees in the program receive a year of palliative care training after completing their initial fellowship in pediatric hematology and oncology. Currently, only five such programs exist nationwide.

Baker and his team are also working to continuously integrate palliative care educational sessions into the core training curricula throughout the hospital.

“There is always going to be a need for the additional resources of a palliative care team, but integrating palliative care principles into the education of future oncologists is important because the best people to provide the highest-quality palliative care are the primary oncology team,” Baker says.

The team also partners with other hospital programs on collaborative studies and has worked with the St. Jude International Outreach

Program to educate staff at partner sites about quality-of-life issues.

Palliative care research

The division aims to integrate palliative care earlier in a patient’s treatment journey by introducing a number of clinical trials—many of which focus on how the service affects patient outcomes and how it is being received by patients and families.

“A huge amount of research is needed to develop and find ways to standardize and improve care,” observes Deborah Gibson, Qualify of Life and Palliative Care clinical research associate.

The team has made significant discoveries and has won two national research awards in such areas as:

- parent support,
- symptom management,
- informed consent and
- end-of-life decision making.

Baker and Deena Levine, MD, who leads the division’s research on ethics and decision-making, plan to further explore how early integration of care affects outcomes.

A global resource

Developing a comprehensive program that serves as a model for other quality-of-life and palliative care programs throughout the world is an ongoing process. As the division grows, its staff seeks new ways to integrate care while educating clinicians, working with families and studying the impact of these methods on the lives of patients.


“All of these efforts combine to help kids have good days,” Baker says. “Our goal is to become a worldwide resource in finding the best ways to make that happen.”●

For more information, visit:
www.stjude.org/quality-of-life.

PETER BARTA



Quality of Life specialists Karen Williams, NP (at left), and Angela Snyder, NP, discuss the best resources to offer a patient’s family.



Recent findings from the Pediatric Cancer Genome Project shed new light on the genetic missteps that lead to AMKL, the type of cancer Alayna Baldwin battled.

Next-Generation Discoveries

BY MARY POWERS

The Pediatric Cancer Genome Project may help parents and scientists better understand the genetic mistakes that give rise to cancer.

When 6-year-old Alayna Baldwin's cancer was discovered and she began treatment at St. Jude Children's Research Hospital, her parents were stunned and anxious. "You would think you'd have a hint," Alayna's mother Marla says. "But she had never been sick, not even a cold. The diagnosis was such a shock. Your whole vision of her life suddenly changes."

Fast forward almost five years. Alayna's hair, once lost due to chemotherapy, flows halfway down her back. The months she spent in isolation following a 2008 bone marrow transplant for an uncommon subtype of acute myeloid leukemia (AML) are a dim memory. Today, Alayna rides bicycles, gets dirty playing outdoors and paints her dog's nails. And, now, thanks to the St. Jude – Washington University Pediatric Cancer Genome Project, doctors know more about mistakes that give rise to the cancer Alayna had.

In the past three years, the Pediatric Cancer Genome Project has provided not only new details about the mutations that underlie the development and growth of a range of childhood cancers, but has also

laid the scientific foundation for improved diagnostic testing and the next generation of more effective, less toxic therapies.

Pediatric Cancer Genome Project

COURTESY OF SHUTTERSTOCK



The Pediatric Cancer Genome Project has harnessed **next-generation sequencing technology** to advance our understanding of some of the most aggressive and poorly understood childhood cancers and to build the foundation for new, more targeted therapies.

Such sequencing involves determining the exact arrangement of all **3 billion-plus chemical bases** of human DNA.

Cancer cells have changes in their DNA relative to normal cells. To identify these changes, the project has deciphered the complete cancer and normal genomes of **about 700 pediatric cancer patients**.

Comparing the two genomes from many patients with the same cancer has helped researchers identify **genetic mistakes** that give rise to different cancers, as well as the missteps that help to fuel its growth and spread. Scientists are already working to translate the discoveries into new ways to find and treat the disease.

“This project has generated more discoveries than we thought possible,” says James Downing, MD, the hospital’s scientific director and the project’s leader at St. Jude. **“The data emerging are laying the groundwork for significant improvements in our ability to diagnose and ultimately treat pediatric cancer.”**

For more information, visit www.stjude.org/pcgp.

Three recent results from the Pediatric Cancer Genome Project have exciting implications for the future of cancer research and treatment:

Scientists have discovered a genetic mistake responsible for a significant percentage of acute megakaryoblastic leukemia (AMKL) in children.

AMKL, the disease Alayna battled, accounts for about 10 percent of pediatric AML.

James Downing, MD, St. Jude scientific director and the Pediatric Cancer Genome Project’s St. Jude leader, was senior scientist in a study that found almost 30 percent of patients with this subtype of leukemia have cancer cells that produce an abnormal protein.

Investigators linked the protein to the rearrangement of chromosome 16. The rearrangement brings together the front end of a gene for making a blood protein and the back end of a gene not previously linked to cancer. That gene makes a protein normally produced only in kidney cells. The result is called a fusion protein.

When researchers introduced the fusion protein into a variety of laboratory models, the protein switched on genes that drive immature blood cells to keep dividing long after normal cells have died. Such unchecked cell division is a hallmark of cancer.

Not only did researchers discover that the fusion gene contributes directly to cancer development, but scientists also found that patients with the mistake were more likely to fail therapy.

Now St. Jude investigators are beginning the task of translating these discoveries into treatments for patients.

“We are collaborating with the Department of Chemical Biology and Therapeutics to identify compounds that are effective against this leukemia subtype,” says Tanja Gruber, MD, PhD, a St. Jude oncologist who helped lead the AMKL study.

The Pediatric Cancer Genome Project played an important role in the discovery of the genetic basis for a high-risk form of leukemia known as hypodiploid acute lymphoblastic leukemia (ALL).

Charles Mullighan, MBBS(Hons), MSc, MD, led the multi-institutional study confirming that the cancer has distinct subtypes that are distinguished by the number of chromosomes lost and the submicroscopic genetic alterations they harbor.

Almost all human cells carry DNA condensed

into 46 chromosomes, half from each parent. But the major hypodiploid ALL subtypes—low hypodiploid ALL and near haploid ALL—carry significantly fewer. Near haploid ALL has 24 to 31 chromosomes. Low hypodiploid ALL has 32 to 39.

Among the newly discovered mutations in this high-risk leukemia, researchers found virtually all patients with low hypodiploid ALL had mistakes in a gene named *TP53* that helps suppress tumor formation. More than one-third of these mutations were inherited. That was the first evidence that low hypodiploid ALL is likely a manifestation of Li-Fraumeni syndrome. The syndrome leaves affected individuals at high risk of developing a variety of cancers and makes them candidates for stepped-up cancer screenings.

Researchers reported that both low hypodiploid and near haploid ALL are sensitive to a family of chemical compounds that block the proliferation of cancer cells by switching off a key pathway in the cells. The group included drugs already used to treat other cancers. Researchers are now testing these and other drugs in additional laboratory models.

The project's scientists also found a new use for DNA sequences previously dismissed as a nuisance.

In this study, scientists focused on telomeres, the repetitive segments of DNA at the ends of chromosomes. Telomeres are widely recognized as playing an important role in chromosomes and human health. But unlike other parts of the human genome, telomeres all have the same six-letter DNA sequence. That means researchers mapping the entire genomes typically dismissed this DNA as “junk” because telomeric DNA could not be assigned to a particular spot in the genome.

Jinghui Zhang, PhD, of Computational Biology, credits postdoctoral fellow Matthew Parker, PhD, with recognizing a simple but powerful solution. Rather than worrying about mapping telomeric DNA, Parker suggested focusing instead on the volume of telomeric DNA, particularly changes between normal and cancer cells. The strategy helped researchers to link mutations in a gene named *ATRX* to increased telomeric DNA in patients with a high-risk form of neuroblastoma.

“The telomere findings gave us information about the mutation’s impact that otherwise would have been difficult to get,” Parker says.

The latest findings came amid planning for Phase II

of the Pediatric Cancer Genome Project. The next stage will build on the lessons and surprises revealed in the course of successfully completing one of the hospital’s most ambitious efforts.

Downing says the next challenges include learning how to transform this powerful technology from a research finding into a clinical tool.

Focusing on the future

While St. Jude researchers work on these projects to help future patients with hard-to-cure diseases, Alayna prepares to celebrate her fifth year as a cancer survivor. Donde Baldwin, Alayna’s father, recalls hours spent traversing the halls of the hospital pushing his then-toddler daughter’s intravenous pole and coaxing her to eat. Today, Alayna has to be reminded not to run and hug a nurse who asks about Froggy, the stuffed frog who endured every aspect of Alayna’s cancer treatment right along with her.

“Alayna always loves coming to St. Jude; she did even as a toddler. She still tells everyone that St. Jude is her hospital,” Marla Baldwin says. “We feel like she’s won the battle. St. Jude has given her the chance to accomplish what she wants to in life.”●



James Downing, MD, St. Jude scientific director, discusses recent results from the Pediatric Cancer Genome Project with St. Jude oncologist Tanja Gruber, MD, PhD.



A Partner in the Journey

BY ELIZABETH JANE WALKER

A parent-led initiative offers support to new families dealing with cancer diagnoses.

PAIR Mentor Rebekah Grant (at left) visits with St. Jude parent Shanda McLin. Rebekah is one of a cadre of highly trained St. Jude parents who volunteer to help new arrivals tread the unfamiliar landscape of a cancer diagnosis.

When 3-year-old Kayden McLin celebrated the end of chemotherapy at St. Jude Children's Research Hospital last year, his parents breathed a collective sigh of relief: "No more chemo! Let's resume our lives," they thought. But to their horror, the next set of scans indicated a recurrence of the kidney cancer called Wilms tumor.

With shaking hands, Shanda McLin immediately paged Rebekah Grant, a mentor assigned to the McLin family through the hospital's PAIR Mentor program. As a fellow St. Jude mom, Rebekah understands the roller coaster of emotions that occur during cancer treatment.

"Rebekah was the person to calm me down when I was falling to pieces," Shanda says. "She walked my husband and me through that horrible time."

Rebekah is one of a cadre of highly trained St. Jude parents who volunteer to help new arrivals tread the unfamiliar landscape of a cancer diagnosis. The program's title offers an indication of its breadth and depth: PAIR is an acronym for Parents Assisting, Inspiring and Reassuring. The initiative, which began more than a year ago, offers a lifeline for parents as they embark on a journey that can be scary, confusing and tumultuous.

The mentors say they derive a sense of fulfillment by partnering with the new arrivals.

"I feel like this is my way to give back," says Rebekah, whose son, Sam, underwent treatment for the eye cancer retinoblastoma several years ago. "The immediate bond between mentor and mentee is amazing."

No matter your socioeconomic status, race or religion, as soon as you tell these families that you've been there, it's an instant connection. It's vital for the patient's health, as well as for the parents' mental and physical health, to know that they have a partner in this journey and that they're not alone."

Parents helping parents

Shanda and her husband, Michael, met Rebekah soon after their arrival at St. Jude.

"It was ironic, because I was telling my husband that it would be nice to find a parent we could talk with who had already been through this experience," Shanda says. "About two minutes later, a lady walked in the door and said, 'We're offering a new parent mentoring program. We were wondering if you'd like to enroll in it.' I signed up, and that same night, Rebekah called. We hit it off immediately. She's always helpful. If she doesn't know something, she tries to find it out. Most of all, she's a shoulder to cry on. Whenever I need her, she's always there."

"There have been times when I was really lost; I was at the end of my rope. Talking to her helped me to hang on."

chaplains, physicians, nurse practitioners and other staff formed a task force. These individuals worked together to design the program, create training materials, and recruit and train parent mentors. The group also outlined a series of checks and balances that protect both the mentor and the mentee.

Passionate partners

Mentors in the program avoid offering medical or psychological advice, according to Kathryn Berry

The PAIR Mentor program was the brainchild of three St. Jude moms who benefited from having informal mentors when their children were undergoing treatment. "Wouldn't it be great if St. Jude had a formal mentoring program?" they asked. The hospital's Family Advisory Council championed the idea, supported by staff from across the institution. Parents, social workers,

Carter, director of Volunteer Services. "They provide a good listening ear, support, and hope and encouragement to these new families," she says. "They've walked in their shoes, and they can offer guidance."

If the family needs further support—from their chaplain, social worker or medical team, for instance—the mentor notes the issue on an encounter form that is completed after each session. Hospital staff can then address that need.

Participants in the program say the mentors add another layer of care and meet unique needs for socialization and partnership. Mentors often serve as a bridge between families and their care teams, highlighting issues that might never have been revealed through regular hospital interactions.

"The mentor is quick to recognize when a parent is struggling emotionally and needs more support," says Judy Hicks of St. Jude Social Work. "During times like that, the mentor and mentee will discuss the best way to alert the team and to engage the appropriate professional."

Meeting the need

Three parent volunteers have mentored nearly 20 families thus far. Although most families transition out of the program after 12 weeks, some participate for longer periods because of relapses or other extenuating circumstances. Organizers hope to recruit and train additional mentors this spring, which will enable more families to benefit from the program. Patient satisfaction surveys indicate an overwhelmingly positive response from participating families and mentors alike.

"It has been rewarding to see the program grow, to see the families truly benefit, and to know that we're contributing in a unique way to the hospital's mission," Berry Carter observes.

Shanda says her mentor fulfills a role that cannot be filled by friends or hospital staff.

"My friends at home don't have children with life-threatening diseases," she says. "And although the doctors and nurses are wonderful, they haven't been through this with their own children, so they can't give the personal insights that another parent can offer. Rebekah has walked this path, so she's a great resource—so cheerful and positive. There have been times when I was really lost; I was at the end of my rope. Talking to her helped me to hang on."●

Ingram Dismuke is flying high, thanks to St. Jude and the loving support of his sisters, Lindsey (at left) and Madison.

When 3-year-old Ingram was diagnosed with a rare brain tumor, his big sisters sprang into action, raising more than \$220,000 for St. Jude.



Ingram

and His Sibling Stars

BY ELIZABETH JANE WALKER

In the insular solar system of childhood cancer, siblings are sometimes the forgotten planets, wobbling in an erratic ellipse around the son or daughter who is undergoing treatment. Parents, gripped with a sense of panic, naturally focus their emotional energy on the child with cancer. When Ashley and Craig Dismuke discovered that their 3-year-old son, Ingram, had a rare brain tumor, they experienced the gamut of emotions all parents undergo under such circumstances. But the couple made a conscious decision to bring

Ingram's sisters along on the journey. And what a ride it has been.

In March of 2012, Ingram was playing with his friends at preschool when a sudden headache reduced him to tears. The Dismukes assumed their son had sinus congestion or a migraine. But additional headaches followed, accompanied by vomiting and lethargy. Ingram's pediatrician ordered a CAT scan. That afternoon, the physician called Ashley at home.

"You need to go to the hospital right now," he said.



Ingram clowns around with his big sisters, who found a novel way to help their little brother.

“Ingram has a tumor on his brain, and he’s going to need surgery.”

Out of this world

Amid the subsequent whirlwind of tests, hospitalization and neurosurgery, Craig and Ashley began searching for the best place to take their son for further treatment. During their search, they spoke with Amar Gajjar, MD, director of Neuro-Oncology at St. Jude Children’s Research Hospital. After that conversation, the couple obtained a referral to St. Jude.

Meanwhile, Craig’s dad contacted the CEO of another prominent hospital and asked him to identify the preeminent oncologist for childhood brain tumors.

“If you can find a doctor named Amar Gajjar, he’s the best in the world. We get our treatment protocols from him,” the CEO replied.

“The fact that we had a doctor who knows more about children’s brain tumors than anybody else in the world was an affirmation that we were going to the right place,” Craig says. “As a father, that was big, because it freed me to take care of my family and not worry about finding the best treatment options.”

Full circle

At St. Jude, the couple discovered their son had ependymoma, a cancer arising from cells in the passageways that produce and store cerebrospinal fluid. Ingram’s tumor was a type called anaplastic.

“It’s a more aggressive variety of ependymoma with a lower cure rate,” Gajjar explains. Ingram’s treatment

would include 34 rounds of carefully targeted radiation treatments as well as four rounds of chemotherapy.

Craig says the diagnosis brought the family full circle.

“We had been involved with St. Jude at several different levels,” he says. “We are close friends with a family at St. Jude, and our kids had even made lemonade stands to raise money for the hospital. But now we were actually going to have a child there. It’s one of those places that you think, ‘This place is amazing. I hope my child never has to go there.’ Now, all of a sudden, our son was the patient.”

With the assistance of St. Jude Child Life specialists, the toddler and his sisters adjusted to the unfamiliar routines of cancer treatment. Not only did 10-year-

old Madison and 8-year-old Lindsey learn about the crucial role siblings play in the experience, but they also participated in Sibling Star Day—an annual red-carpet event that applauds brothers and sisters for the sacrifices they make. Craig and Ashley made a conscious effort to include Ingram’s sisters in other ways, as well.

A family affair

The Dismuke family has always led an active lifestyle. After undergoing surgery for a serious heart problem several years ago, Craig began training for a marathon. His goal was to complete the half marathon portion of the 2011 St. Jude Memphis Marathon Weekend. The entire family trained for the race, with the girls riding their bikes alongside their parents, who pushed Ingram in a stroller.

“When Craig ran through the St. Jude campus in December of 2011, he never dreamed that the following year he would be bringing his son here for treatment,” Gajjar muses. “It was kind of fate.”

After the marathon, Madison approached her parents. “I want to run next year, and I want to raise money for St. Jude,” she said. Soon after that conversation, Ingram received his diagnosis.

“Well, we’re definitely doing it now,” Madison announced, “and it’s going to be Team Ingram.”

Craig and Ashley thought that was a great idea. Not only would the activity give the children a way to support a worthwhile cause, but it would help them feel involved. “It would be the girls’ way to help,” Ashley says. “They could pray for Ingram; they could love him;

“The fact that we had a doctor who knows more about children’s brain tumors than anybody else in the world was an affirmation that we were going to the right place.”

but they couldn’t do anything physical to help him.”

Then the girls began negotiating. “If we raise \$100,000,” they said, “can we have a TV in our room?”

Craig and Ashley decided that if the girls were mature enough to meet that goal, they should be able to exert discretion in their TV viewing habits.

“OK,” Craig said, “but you’re not getting cable.”

“Well, if we raise \$200,000, will you give us cable?”

The couple sighed. “Why not?”

A nationwide approach

Madison and Lindsey did the math: If they raised \$100 a day selling lemonade, it would take them 1,000 days to raise \$100,000. However, if they could talk to business executives, they might be able to raise money more quickly.

The girls practiced their presentation, and their dad helped them set up appointments. Slowly, the donations started to roll in.

To accelerate their progress, the girls created a video that could be posted online. A local video producer donated the technical expertise; the savvy young fundraisers provided the talent.

During Ingram’s first inpatient chemotherapy treatment, Craig and Ashley were anxious and concerned about their son. “Being inpatient for chemo is one of those tough emotional times that you really can’t explain,” Craig says. One evening, Ashley lay on the couch in the hospital room while Craig reclined with his laptop computer. Idly, he repeatedly hit “refresh” on the girls’ fundraising site.

“All of a sudden, the total jumped to \$50,000,” Craig recalls. The owner of the largest car dealer in Texas had made a \$20,000 donation.

“We were really excited. That lifted our spirits,” Craig continues. “Then, as people started seeing the video, they began sending in \$100; \$2,000; \$5,000. It was amazing; the girls ended up raising more than \$220,000.

“They got a TV, needless to say.”

The whole, wide world

Thus far, Ingram has had a fairly smooth course of treatment, with mild side effects from chemotherapy and radiation. With the help of physical therapy and speech therapy, he has regained his strength and has overcome minor articulation issues. “He’s doing great,” Gajjar reports. “He just came in for a follow-up, and everything was fine.”

The talkative 4-year-old is enthralled by dinosaurs, swords, art and baseball.

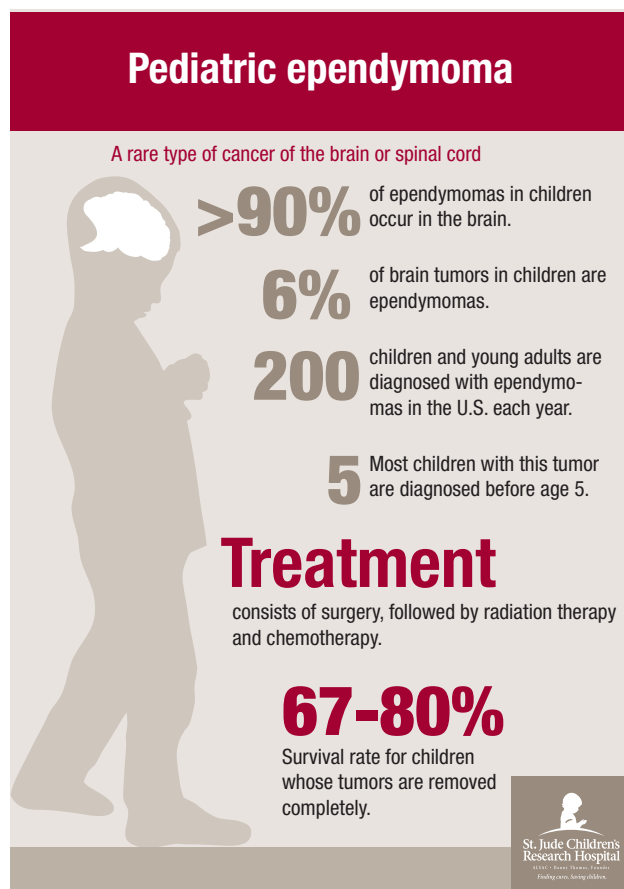
Baseball, above all.

“I try to hit it, and sometimes I don’t hit it, and I swing so hard and I can’t hit it. It comes fast, and I make my bat go fast,” explains Ingram, words tumbling over one another in an excited rush.

What else does he like? Once, during treatment, someone asked Ingram where he would visit if he could travel anywhere in the whole, wide world.

His answer was immediate and enthusiastic: “St. Jude!” he exclaimed.

View excerpts from Madison and Lindsey’s fundraising video: www.stjude.org/Promise. ●



Pediatric ependymoma

A rare type of cancer of the brain or spinal cord

- >90%** of ependymomas in children occur in the brain.
- 6%** of brain tumors in children are ependymomas.
- 200** children and young adults are diagnosed with ependymomas in the U.S. each year.
- 5** Most children with this tumor are diagnosed before age 5.

Treatment

consists of surgery, followed by radiation therapy and chemotherapy.

67-80%

Survival rate for children whose tumors are removed completely.

St. Jude Children's Research Hospital
1000 West Clinch Street
Memphis, Tennessee 38103
800.427.2722

Kie'a Boyce doubles as patient and MRI technologist during medical play with St. Jude Child Life Specialist Katherine Bailey. In a recent study, Bailey found that children who underwent targeted preparation and support procedures before MRI testing were eight times more likely to complete the test without general anesthesia than those who did not receive preparation.



ANN-MARGARET HEDGES

Coping Plans *for* Easier Scans

A St. Jude support program helps children with sickle cell disease sail through their MRI scans without anesthesia.

BY JOYCE M. HARRIS

The day of her most recent magnetic resonance imaging (MRI) exam at St. Jude Children's Research Hospital, Kie'a Boyce seemed oblivious to smiles and curious glances as she boogied her way across campus—from the Hematology Clinic, through the hospital's winding corridors and into the diagnostic imaging suite. The 9-year-old could not resist the urge to shake, twist and wiggle.

"She danced all the way to the Chili's Care Center," says her mother, Eva Curtis.

With the squirming out of her system, Kie'a remained motionless for an entire hour as the MRI machine captured 3-D images of tiny vessels in her brain. The exam was necessary to evaluate how well she was responding to treatment for sickle cell disease.

The little girl's pre-scan dance routine was not just a fun diversion—it

was also a specific coping mechanism designed to help Kie'a cope with the upcoming medical procedure. The tailored interventions she had received beforehand prepared her to stay relaxed and motionless during the hour-long scan.

No-fidgeting zone

MRI scans of the brain and liver are routine for children with sickle cell disease. The key to a successful MRI scan is immobility: No squirming or fidgeting. Until recently, many young patients required general anesthesia because of their tendency to move during lengthy MRI scans. However, children with sickle cell disease are at greater risk for anesthesia-related complications. By avoiding general anesthesia during exams, they experience fewer hospital admissions and emergency room visits.

At St. Jude, children as young as 5 years old have a greater chance of completing their scans and avoiding general anesthesia thanks to tailored preparation and support procedures available through the hospital's Child Life program.

Kie'a arrived at St. Jude for treatment at age 5 after sickle cell disease caused frequent episodes of painful swelling in her hands, arms and feet.

"It was horrible," Curtis recalls. "She was hospitalized for pain crises two to four times a month for three or four days at a time."

Those days are behind Kie'a, thanks to her involvement in a clinical trial that uses the drug hydroxyurea to prevent the painful episodes. Since arriving at St. Jude, Kie'a has learned as much about sickle cell disease as she has about her favorite subjects in

her third-grade class. The knowledge has empowered her to make informed decisions about her care and treatment, specifically about her MRI experience.

Preparing for the big day

St. Jude Child Life Specialist

Katherine Bailey meets with sickle cell patients and families several weeks before their scheduled MRI exams to discuss possible barriers to completing scans. Together, they develop coping plans to overcome a fear of confined spaces, a sense of isolation during the exam, or the loud noises that occur during the imaging process. Bailey's goal is to remain two steps ahead of such hurdles, which sometimes haunt children's active imaginations.

"Kids come up with lots of scary possibilities," Bailey says. "Some think the moving MRI table will go out the other side and fall over. They become tearful from talking about it. My job is to get ahead of their fears and anxieties. If they understand the process, they can prepare themselves emotionally and develop internal coping strategies for how to get through the procedure successfully."

After identifying possible obstacles, Bailey introduces patients to the sights, sounds and essentials of MRI testing. She shares a photo book of the MRI suite as well as pre-recorded MRI sounds. Photos of sample scans illustrate how motion can distort the images doctors rely on to detect early signs of stroke and iron overload from chronic blood transfusions.

To help curb movement, Bailey encourages patients to dance and move about freely during training before guiding them through exercises that help them lie still. Bailey's lucid explanations and hands-on coping techniques demystify the MRI process for both patients and their parents.

"As parents, we don't always know the best way to explain the procedures to them," Curtis says. "It's great that Kie'a and other patients have been trained and know what to expect."

"If they understand the process, they can prepare themselves emotionally and develop internal coping strategies for how to get through the procedure successfully."

Practice makes perfect

Kie'a was all ears during her training and proved it during medical play with a model MRI machine. The session is Bailey's litmus test to assess how well patients grasp the information.

"I have to strap you in," Kie'a says, positioning the doll gingerly onto the model MRI table. "Your head is going to be in the helmet, and you have to be very still so we can take pictures."

Before ending the session, patients designate an adult to join them in the exam room for moral support. They select their favorite movie, music or audiobook to pass the time during the procedure, and decide whether a squeeze ball will be helpful when the urge to move arises. Gripping the ball focuses movement in the hand and away from the testing site.

For Bailey, there are no limits when it comes to showing compassion and calming jittery nerves.

"I've read books to patients during MRI exams," she says, "Hearing a familiar voice and knowing that they are not alone during the exam is comforting for many patients."

Measurable benefits

Bailey's personal touch caught the attention of Jane Hankins, MD, of the St. Jude Hematology Clinic. As one of several investigators advancing treatment and improving the quality of life for patients with sickle cell disease, Hankins looked at Child Life's tailored interventions with a scientific eye.

"I noticed that the patients

Katherine worked with were young, and they tolerated the MRI well without general anesthesia," Hankins says. "I suggested we look at the data to see if there is scientific evidence that what she is doing is beneficial to the patients."

The pair assessed data from 71 children, ages 5–12, who had sickle cell disease. The results revealed that children who received the short preparation program before MRI exams were eight times more likely to complete the scans without general anesthesia than were patients of the same age who did not receive the preparation. The findings were published in the journal *Pediatric Radiology*.

Preparation and support procedures are commonly used in U.S. hospitals, but the St. Jude study is the first of its kind to focus on children with sickle cell disease.

Risk reduction

Today, St. Jude patients with sickle cell disease routinely attend Bailey's training sessions to prepare for MRI exams. General anesthesia is reserved for urgent cases or for children who are unable to complete scans despite preparation. In those instances, preventive measures are taken to prevent anesthesia-related complications.

"Each time we avoid putting patients under general anesthesia, we avoid the additional risks to patients and eliminate the burden for families," Hankins says. "What Child Life has done is a great example of the collaboration that exists at St. Jude."●

The **Power** of Friendship

For more than 40 years, ESA has put heart into the St. Jude mission.

BY LEIGH ANN ROMAN

The service organization Epsilon Sigma Alpha (ESA) is part of the extended family of St. Jude Children's Research Hospital. ESA has been part of the St. Jude story since 1972, when the organization adopted the hospital as its international service project. St. Jude founder Danny Thomas visited the 1970 national ESA convention, where he was made an honorary member. For the rest of his life, he attended nearly every national ESA convention to thank the members for their work.

"We were there at the beginning of Danny's dream," says B.J. Clark, executive director of ESA. "It always was sort of a personal relationship with Danny and with the people at ALSAC [the hospital's fundraising organization]."

Making that personal connection is at the heart of ESA, which now has more than 10,000 members worldwide. "What makes us different from other service groups is that we have always done all of our projects with the power of friendship," Clark says.

Tom Desmond, a regional director for ALSAC, says ESA members are involved in countless St. Jude events, and members have frequently traveled more than 100 miles to help with fundraisers. "What sets ESA members apart is their thorough understanding of the mission and their dedication to St. Jude," he says. "I know that whenever we have a challenge in getting volunteers for an event, we have ESA members we can call on who are willing to travel and help."

Former St. Jude patient Lindsey Tercilla discovered the power of ESA as a member of the collegiate chapter at the University of Florida-Gainesville, where she serves as the chapter's philanthropy chair.

"ESA is possibly the best thing that has happened to me in my collegiate career," says the pre-law student.



Former St. Jude patient and ESA member Lindsey Tercilla hugs Corban Carr, who is receiving treatment at St. Jude for rhabdomyosarcoma.

"It's a lot of service work, and it's hard work, but it is also a lot of fun."

At age 2, Tercilla was referred to St. Jude for treatment of a tumor called lymphangioma. Surgeons removed the growth, along with part of her small intestine. Thankfully, the tumor was benign, and no further treatment was required. But the experience made a lasting impression on her family.

Joining ESA and being part of the group's February "ESA ♥ St. Jude" campaign, she says, "has been an incredible opportunity to pay it forward."

ESA's dedication to St. Jude is matched only by its impact. "ESA is proud of our 40-year commitment and even more proud of the more than \$165 million that we have raised for St. Jude," says Suzy Winters, ESA International Council president. "We are committed to St. Jude not only because of our history, but because of what the future can hold. We are optimistic that St. Jude is going to find cures, and we want to be around when that happens." ●

Research Highlights

DNA variations linked to relapse risk

One of the largest studies of the role inherited genetic variation plays in the treatment outcome of young acute lymphoblastic leukemia (ALL) patients has linked more than 100 common differences to an increased risk of relapse.

Investigators hope the discovery will lead to better detection of young ALL patients facing the highest odds of relapse and new strategies for preventing it.

A substantial number of children with ALL relapse even though they are considered at low risk based on current factors. Of those who relapse, fewer than half are still alive after five years. More accurate risk classification would help clinicians individualize therapy and improve survival for these patients.

The study, led by St. Jude investigators, identified 134 small, common variations in genes as predictors of relapse.

Among those findings, scientists discovered that a single change in the *PYGL* gene was associated with nearly a four-fold increased risk of relapse.

Jun J. Yang, PhD, Pharmaceutical Sciences, was first author of a report on this project, which appeared in the journal *Blood*. Mary Relling, PharmD, Pharmaceutical Sciences chair, was senior author.

“Most cancer specialists have concentrated their work on the genetic variations of the cancer cells themselves that identify higher-risk forms of leukemia,” Relling said. “Our study shows that genetic variations that are inherited from the parents—variations that make us differ from each other—also play a big role in why leukemia relapses occur in some patients but not others.”



Masters of the mask

Jason Garrett Jr. and Payton Buford Peter create Mardi Gras-themed masks and decorations in the Patient Care Center lobby to celebrate Fat Tuesday. In the Mardi Gras event organized by the St. Jude Child Life program, children donned masks and paraded through the hospital's hallways, as cheering employees distributed beads and high-fives.

Scientists unfold mysteries of cell-suicide pathway

Like a cat that loosens its grip just long enough for a mouse to escape, a protein named PUMA frees the pivotal tumor suppressor protein p53, researchers have discovered. The escape activates a pathway that leads cells to self-destruct.

That finding may help scientists in their ongoing efforts to harness the body's cell-suicide (apoptotic) machinery to get rid of tumor cells.

St. Jude researchers reported that PUMA acts through a mechanism called regulated unfolding to set p53 loose to switch on the apoptotic pathway. The body uses apoptosis to eliminate damaged, unneeded or unwanted cells, including emerging tumor cells. Investigators found PUMA induces partial unfolding of

BCL-xL, a protein that normally binds p53 and keeps this critical tumor suppressor under wraps.

The findings were published in a recent issue of *Nature Chemical Biology*.

The results build on previous St. Jude research on how apoptosis is regulated. The work also suggests that regulated unfolding is a general mechanism that likely controls signaling along other pathways in cells. Richard Kriwacki, PhD, of St. Jude Structural Biology, and Douglas Green, PhD, Immunology chair, are the study's co-corresponding authors.



Visiting Memphis? Give blood or platelets

Dan Medley relaxes during a recent donation at the St. Jude Blood Donor Center. Located within the hospital, the facility helps ensure that St. Jude patients always have access to blood products.

“About 1,000 blood product transfusions are performed during a typical month at St. Jude,” said Kimberly Foster (pictured at right) of the Blood Donor Center. “Each unit of donated whole blood saves the hospital about \$250, which is what one unit costs if it must be purchased from an outside source. Each platelet donation saves St. Jude between \$500 and \$700.”

For more information, visit www.stjude.org/blood-donor-center or call 1-866-278-5833, ext. 2024.



SETH DIXON

Researchers study effects of drug shortage

St. Jude has blown the whistle on the impact that drug shortages can have on children receiving cancer treatment.

Monika Metzger, MD, of St. Jude Oncology, led a multi-institutional team that studied what happens to children who must receive substitute cancer-fighting drugs because of national drug shortages.

The researchers found that two-year cancer-free survival for children, teens and young adults enrolled in a Hodgkin lymphoma clinical trial fell from 88 to 75 percent after the drug cyclophosphamide was substituted for mechlorethamine. The patients were receiving treatment for intermediate- or high-risk

disease. The substitution occurred after a mechlorethamine shortage that began in 2009.

No patients in the study died, but those who relapsed received additional intensive therapy that is associated with higher odds for infertility and other health problems later.

An analysis comparing how patients in each group were faring two years after their cancer diagnoses appeared in the *New England Journal of Medicine*. The report provides the first evidence of a drug shortage adversely impacting treatment outcomes in specific patients. St. Jude led the study for the five institutions in the Pediatric Hodgkin Lymphoma Consortium.

Discovery points way to revised screenings

St. Jude researchers have found evidence that chest irradiation may leave some adult survivors of childhood cancer in danger of developing pulmonary hypertension during middle age.

Childhood cancer survivors treated with chest irradiation or certain chemotherapy drugs are known to be at risk for a variety of treatment-related heart problems. But the study, published recently in the *Journal of Clinical Oncology*, is the first report suggesting survivors might also face higher odds of developing pulmonary hypertension. Pulmonary hypertension is a serious, progressive form of increased pressure in the arteries in the lungs.

First author Gregory Armstrong, MD, of St. Jude Epidemiology and Cancer Control, said pulmonary artery pressure was elevated in 25 percent of adult survivors in the study who had received chest irradiation.

The findings suggested the survivors might be at higher risk of pulmonary hypertension. Researchers also found that the risk climbed with increasing radiation dose and was associated with decreased exercise endurance.

This finding represents important information for clinicians monitoring cardiovascular health of adult survivors of childhood cancer.

Highlights



On-stage serenade

A.B. Quintanilla, lead singer of Kumbia All Stars, serenades St. Jude patient Yazleemar Gonzalez Santana during the 11th annual *Promesa y Esperanza* Seminar. Latin music artists, representatives from 15 Spanish-language TV stations and many celebrity guests joined St. Jude radio partners for the event. Since its inception in 1997, *Promesa y Esperanza* has raised more than \$88 million for the hospital.

Scientists aim to protect vulnerable patients from flu

Doubling the doses of pandemic influenza vaccine and booster shots gave children and young people infected with the human immunodeficiency virus (HIV) enhanced protection against the 2009 H1N1 pandemic flu virus, according to a national study led by St. Jude investigators. The approach sparked antibody production sufficient to protect more than 80 percent of participants against the pandemic flu strain.

The findings suggest the same strategy might help protect vulnerable patients in future flu pandemics. Individuals with immune systems weakened by cancer treatment, HIV infection or other causes are at greater risk of contracting the flu and are more likely to require hospitalization.

Patricia Flynn, MD, Infectious Diseases, is the first and corresponding author of the research, which was published in

the *Journal of Infectious Diseases*.

The study is one of two published recently that reflects ongoing efforts at St. Jude to develop new, more effective strategies to protect patients against flu infections. Hana Hakim, MD, Infectious Diseases, is first and corresponding author of the second study, which appeared in the journal *Vaccine*.

Work continues on making flu vaccinations more effective for high-risk patients. Hakim said it remains important for those who care for or live with these children to be vaccinated.

“Because of their weak immune systems, if these children are exposed to the flu they are more likely to catch it. If they become infected, they are more likely to be hospitalized for complications than healthy children are,” Hakim said.

St. Jude receives national honors

St. Jude recently received kudos from two national magazines. The hospital was recognized for the third consecutive year by *FORTUNE* magazine as one of the “100 Best Companies to Work For.” Hospital employees consistently cite the pride they have in the St. Jude mission as a top benefit.

“Our 50 years of progress has come from teamwork, and our employees know that regardless of which department they work in, they are valued and they understand their efforts contribute directly to achieving our mission,” said Dr. William E. Evans, St. Jude director and CEO.

St. Jude was also named one of the best cancer care

hospitals in the country by *Parents* magazine. Based on published research data, St. Jude has the best worldwide outcomes in a number of pediatric cancer categories, including acute lymphoblastic leukemia, acute myeloid leukemia and medulloblastoma.

“Being recognized is always a great honor, especially since our focus on some of the toughest pediatric cancers often makes comparisons difficult,” Evans said. “This recognition is a tribute to the tireless dedication of all of our physicians, researchers and staff who help families facing the most challenging times imaginable.”

One Tough Cookie

Sweet treats become a weapon in the battle against childhood cancer.



Gretchen Witt has parlayed her love for cookies into more than \$4 million for pediatric cancer research.

BY KERRY HEALY

Like Goliath's David, Gretchen Witt is facing a giant and powerful adversary—but unlike the biblical hero, Gretchen isn't armed with a slingshot. Instead, she's waging her battle with an army of what she calls "Good Cookies."

Gretchen and her husband, Larry, are co-founders of the nonprofit foundation Cookies for Kids' Cancer. The inspiration for the organization came when their son Liam had neuroblastoma, a cancer of the nervous system.

Watching Liam battle cancer made Gretchen determined to do something.

"Learning that pediatric cancer kills more children than cystic fibrosis, muscular dystrophy, AIDS, asthma and juvenile diabetes combined was shocking to me," she says. "How could I sleep at night if I didn't at least try to do something to help?"

The organization raises awareness while helping support the research of St. Jude Children's Research Hospital.

"I am honored when a patient's family gets involved, because they know the pain of pediatric cancer, but if I can get someone interested who has no connection to childhood cancer, it means we're getting the word out to a broader audience," Gretchen says.

Cookies for Kids' Cancer began in 2007 with Gretchen's idea to host a larger-than-life cookie sale, selling 96,000 cookies. The organization blossomed by offering gourmet cookies and gifts as well as by inspiring individuals to host bake sales and fundraisers. To date, Cookies for Kids' Cancer has granted nearly \$4 million to St. Jude and other institutions for pediatric cancer research.

So, why cookies?

"We wanted a concept that gives everyone a simple way to join the fight, and who doesn't love cookies?" Gretchen says. "Cookies for Kids' Cancer has become much more about the people, the Good Cookies, fighting for improved treatments for children every day."

The organization's Medical Advisory Board has awarded St. Jude three sizeable grants for research targeting acute lymphoblastic leukemia, medulloblastoma and neuroblastoma. The board identifies critical research needs across 12 distinct types of pediatric cancers to help bring the most promising therapies to clinic as quickly as possible.

Gretchen says she feels a connection to St. Jude founder Danny Thomas. "It's inspiring how he prayed to St. Jude and really put his heart out there to take action," she says.

Liam Witt lost his battle with neuroblastoma in January of 2011 at age 6. The Witts honor his memory by continuing their fight through the funding of lifesaving work like that of St. Jude.

"St. Jude is the epitome of what's right in the world of pediatric cancer," Gretchen says. "It is truly focused on the well-being of the whole family."

Gretchen is modest about all that her organization has accomplished, saying, "Baking 96,000 cookies is nothing compared to what Liam went through." Her goal, she says, is to help people understand that if she can fight cancer with cookies, they can do something, too. "I just want people to be Good Cookies. I want them to care about this cause and realize that there is something they can do about it."●

Perspective

BY HILL HARPER

Child's Play

A simple game played with a St. Jude patient evokes deep emotion and a determination to help.

When I visited St. Jude Children's Research Hospital a couple of years ago, I was blown away by how creatively the hospital is organized. The environment is welcoming and loving, from the moment you walk through the doors.

But my most memorable moment came during a game of Jenga®—the game where you remove pieces of wood from a tower until everything falls down. I was playing with a little girl who was a patient at the hospital. We were talking about what she was going through—and we were laughing and joking and having fun. This young lady was actually a really good Jenga player—much better than I was. Because I had recently been diagnosed with thyroid cancer, I knew how difficult and frightening and life changing the experience could be for an adult. So I couldn't imagine how courageous and strong this little girl and her parents had to be. It just opened up my heart and blew my mind away.

Playing Jenga with this young woman at St. Jude reminded me of one of my favorite quotes by Dr. Martin Luther King Jr.: "We are all tied together in a garment of mutual destiny." To me, that means no matter how well I may be doing in Hollywood or no matter how well *CSI: NY* may do in the ratings, if there's a young girl at St. Jude who's not doing well, then I'm not doing well.

We're all in this together.

The work that St. Jude is doing and the people who support the hospital's mission represent that concept beautifully. And I couldn't be happier to be a proponent of that.

I was in the midst of writing *The Wealth Cure*, a book about financial literacy, when I was diagnosed with my thyroid cancer. It really made me focus on what creates true wealth in our lives. At the end of the day, what I discovered through my journey with cancer was that true wealth is our health. Our future is our children. If we buy into this idea that health is most important, then figuring out a way to solve the biggest



Actor Hill Harper plays a game of skill, coordination and concentration with St. Jude patient Courtney Davis.

health challenges facing our children should be our No. 1 mission. That's exactly what St. Jude does. And that's where our focus and our support should go first and foremost. I'm proud to support St. Jude. That's why I'm going to polish up my Jenga skills ... and then return for another visit.

An alumnus of Harvard Law School, actor Hill Harper is the author of four books. He portrays Sheldon Hawkes, MD, in the CBS drama CSI: NY.●

Your legacy begins here.



St. Jude patient Kayla:
California girl

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The very fact that you are holding this magazine is proof that you care. In fact, it is because of you that kids like Kayla will have a fighting chance to experience the beautiful moments of their lives. Yes, because of you. Your legacy gift is a powerhouse in terms of research and care. It will allow researchers and doctors to continue to peel away the layers of pediatric cancer and other deadly childhood illnesses. Let this be your legacy: that one day no child will die in the dawn of life. Join St. Jude in finding cures and saving children.

Begin your legacy today. Call 800-910-3188 or visit stjudelegacy.org.



**St. Jude Children's
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CHANGE SERVICE REQUESTED

Patients, siblings and Child Life staff enjoy the first Spring Fling semi-formal dance, which was held in the Danny Thomas/ALSAC Pavilion. The event, held in conjunction with Mardi Gras, was tailored exclusively for 10- to 14-year-old patients and their siblings.



SETH DIXON

Finding cures. Saving children.