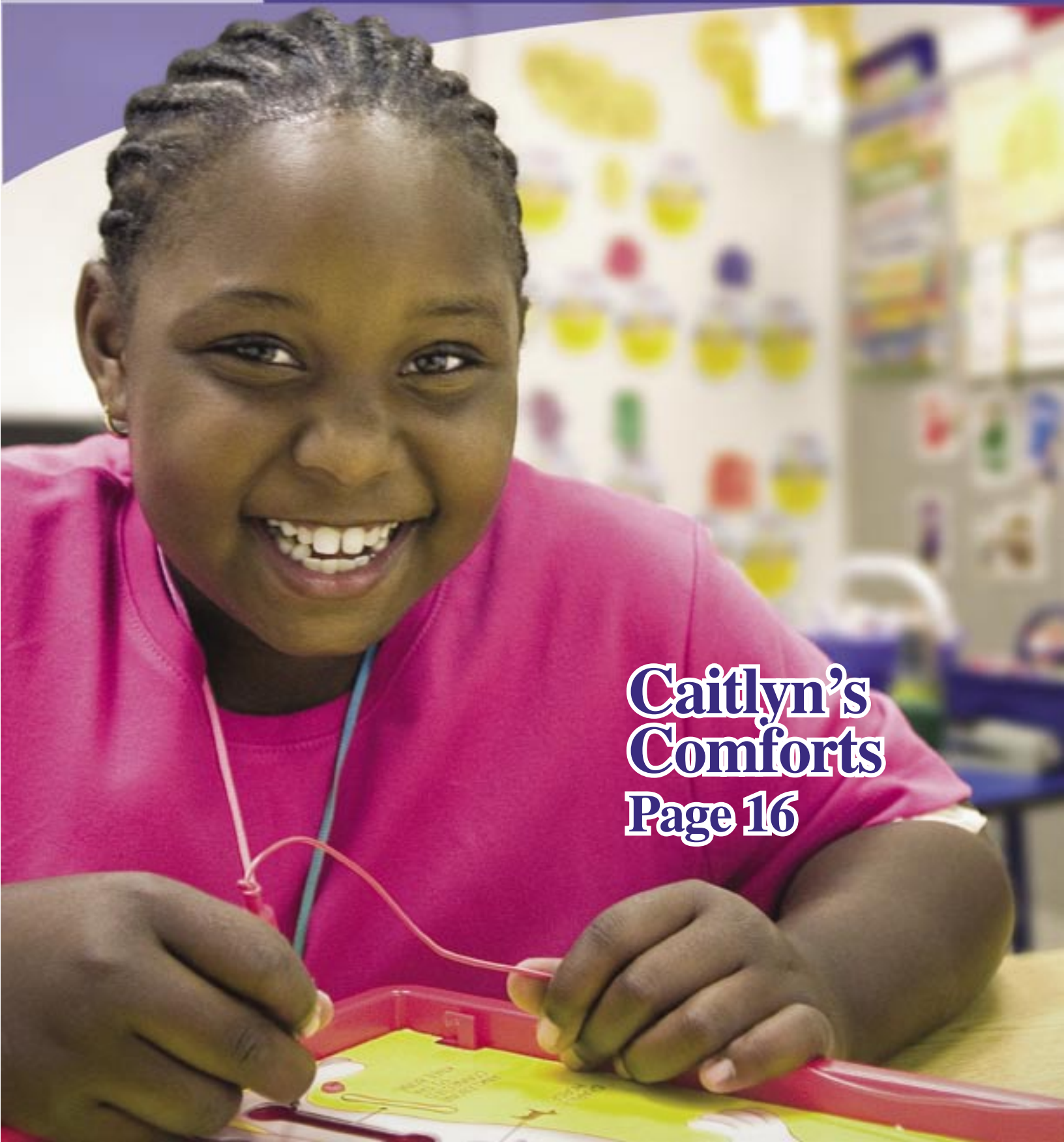


# Promise

Summer 2005



**Caitlyn's  
Comforts  
Page 16**

St. Jude Children’s Research Hospital was founded by the late entertainer Danny Thomas. It opened February 4, 1962. The institution was created because of a promise Thomas made during the depression era to St. Jude Thaddeus, the patron saint of the hopeless.

“Show me my way in life,” Thomas prayed. In return, Thomas promised to build St. Jude Thaddeus a shrine. That shrine became a world-class research institution that treats children regardless of race, color, creed or their ability to pay. This remarkable event also inspired the name of this magazine,

Promise.



St. Jude Children’s Research Hospital, Memphis, Tennessee

Promise

is a quarterly publication of the  
Department of Public Relations  
St. Jude Children’s Research Hospital  
332 N. Lauderdale St.  
Memphis, Tennessee 38105

St. Jude Children’s Research Hospital’s mission is to find cures for children with catastrophic diseases through research and treatment.

- Hospital Director and Chief Executive Officer**  
William E. Evans, PharmD
- ALSAC Chief Executive Officer**  
John P. Moses
- ALSAC/St. Jude Senior Vice President of Communications and Public Relations**  
Jerry Chipman
- Director of Public Relations**  
Judith W. Black
- ALSAC Vice President of Communications**  
George Shadroui
- Publications Manager and Editor**  
Elizabeth Jane Walker
- Art Director**  
Jessica W. Anderson
- Photo Editor**  
Jere Parobek
- Photographers**  
Seth Dixon  
Laura Hajar  
Dale Hawkins  
Evanne Newman
- Contributing Writers**  
Lin Ballew  
Tanuja Coletta  
Joe Hanna  
Marc Kusinitz, PhD  
Victoria Tilney McDonough  
Beth McGowan  
Carrie L. Strehlau
- Guest Author**  
Kallen Esperian
- Editorial Advisory Board**  
Lisa Baker  
Leslie Davidson  
Pat Flynn, MD  
Mark Hendricks  
Marc Kusinitz, PhD  
Ava Middleton  
Carlos Rodriguez-Galindo, MD  
Carrie L. Strehlau  
Penny Tramontozzi  
David Tucker  
Sally Wiard  
John Zacher

Promise

A publication of St. Jude Children’s Research Hospital Summer 2005

Features

- 3 Dollars and Sense**  
Projects underway in the GMP
- 4 Pepper Power**  
Jeff Probst, Chili’s and St. Jude
- 5 A Perfect Match**  
Finding love and inspiration at St. Jude
- 6 A Bonding Experiment**  
Sabotaging bacterial invaders
- 8 No Stone Unturned**  
The St. Jude palliative care initiative
- 10 Sidestepping Stress**  
Fostering recovery by easing parents’ anxieties



13 Bringing out the Superhero in Every Child

Child Life to the rescue

16 Caitlyn’s Comforts

Helping a patient thrive

19 One in a Million

Fighting colon cancer

21 It’s How You Play the Game

Patient James White



Highlights

2 Research Achievements

Perspective

24 Kallen Esperian

Singing the praises of St. Jude

St. Jude Children’s Research Hospital is an Equal Opportunity Employer. For inquiries about stories in this publication, call the Public Relations department at (901) 495-2125 or e-mail [elizabeth.walker@stjude.org](mailto:elizabeth.walker@stjude.org). Visit our Web site at [www.stjude.org](http://www.stjude.org). Articles and photos may be reprinted with permission. ©2005.

On the cover: St. Jude patient Caitlyn Mathis. Photo by Laura Hajar.



# Highlights

## HHMI investigator

Brenda Schulman, PhD, of Structural Biology and Genetics and Tumor Cell Biology, has been named a Howard Hughes Medical Institute (HHMI) investigator. She joins other HHMI investigators Charles Sherr, MD, PhD, Genetics and Tumor Cell Biology co-chair, and James Ihle, PhD, Biochemistry chair.

## Pattern predicts resistance

The discovery of a specific pattern of gene expression linked to multiple-drug resistance of leukemic cells sheds light on why standard therapies fail to cure some children with acute lymphoblastic leukemia (ALL). The finding helps explain why about 20 percent of children with ALL are not cured with the same therapy that cures other children with this disease; it could also lead to development of drugs that would overcome that resistance. William Evans, PharmD, St. Jude director, was senior author of a report on the study appearing in the April 2005 *Cancer Cell*.

## Immune system model

St. Jude scientists have joined colleagues at other institutions to develop a laboratory model of the human immune system. This model will allow scientists to study ways to improve stem cell transplantation without putting patients at risk.

The model will help researchers study how stem cells give rise to various parts of the immune system; how immune cells kill cancer cells and fight infections; and how immune cells respond to treatment. Rupert Handgretinger, MD, PhD, director of Stem Cell Transplantation and co-leader of the Transplantation and Gene Therapy Program, was senior author of a report on the study in the May 2005 *Journal of Immunology*.

## The inheritance factor

St. Jude investigators have discovered that the outcome of chemotherapy treatment for acute lymphoblastic leukemia (ALL) depends not only on the acquired genetic makeup of the leukemic cells, but also on genes that children inherit from their parents. Researchers demonstrated that traits inherited from parents could reduce the effectiveness of some chemotherapy.

The study suggests that it might be possible to design ALL treatment based in part on a patient's inherited genetic makeup. Mary Relling, PharmD, Pharmaceutical Sciences chair, was senior author of a report on this work appearing in the June 2005 edition of *Blood*.

## Cancer-causing combo

St. Jude researchers have learned that the genes *TEL2* and *MYC* cooperate to promote pediatric cases of the immune system cancer B cell lymphoma. In B cell lymphoma, B lymphocytes multiply and crowd out other blood cells. *TEL2* cooperates with *MYC* to increase the chance that a certain additional mutation will occur in precancerous B lymphocytes that will permit the cells to become cancerous.

Gerard Grosveld, PhD, Genetics and Tumor Cell Biology chair, is senior author of a report on this work, which appeared in the March 2005 *Molecular Cell Biology*.

## Natural-born killers

Natural killer immune system cells can be genetically modified to brandish a powerful "on" switch that prompts them to attack and kill leukemic cells, according to St. Jude researchers. The breakthrough suggests a way to improve the outcome of children who receive treat-

ment for acute lymphoblastic leukemia or other blood cancers. A report on this work appears in the March 2005 *Blood*. Dario Campana, MD, PhD, of Hematology-Oncology and Pathology was the report's senior author.

## Better views of tumors

The combination of PET and CT scans appears to be a promising new imaging technique for use in the initial staging of some pediatric sarcomas and in following children after treatment, according to Beth McCarville, MD, Radiological Sciences.

The technique combines the ability to get anatomic information provided by computed tomography (CT) with information on the activity of living tumor tissue provided by PET scans. Sue Kaste, DO, is senior author of a report on these findings, which appears in the April 2005 *American Journal of Roentgenology*.

## Breathe easy

Chronic transfusions of red blood cells appear to be an appropriate first-line treatment for recurring or severe episodes of acute chest syndrome (ACS) in children with sickle cell disease, according to a report published by St. Jude researchers in the March 2005 *Journal of Pediatric Hematology-Oncology*.

ACS, due to a lack of oxygen and/or infection in the lung, is responsible for as many as 25 percent of deaths among patients with sickle cell disease. Winfred Wang, MD, director of the St. Jude Comprehensive Sickle Cell Center, was senior author of the report.

**For more detailed news about St. Jude research, visit [www.stjude.org/media](http://www.stjude.org/media).**

LAURA HAJAR



## Dollars and Sense

To stay afloat, pharmaceutical companies must keep an eye on profits.

But at St. Jude, saving lives is the bottom line.

Imagine that your child has a rare disease. Scientists know how to create a drug that would offer hope. But here's the rub: No company is willing to invest in such a drug because the market is too small.

It all comes down to dollars and cents.

St. Jude Children's Research Hospital has turned that paradigm upside down. In its biomedical workshop called the Good Manufacturing Practices (GMP) facility, scientists produce drugs, vaccines, proteins, gene-based molecules and other biological products based on need, not profits.

Inside the 64,000-square-foot facility, biological products are made in small lots—and can even be made in units of one for individual patients. The facility also has Biological Safety Level 3 laboratories for work with microorganisms that must be carefully contained.

"We work with all St. Jude departments that may have products they want to introduce into clinical trials," explains John Coleman, GMP director and vice president of St. Jude Therapeutics Production and Quality.

"We're the ones who make those products, and we also make sure that federal guidelines and regulations are met when those products are produced," he continues.

Two years after opening, the GMP is now a hub of activity. Major projects underway include:

- **Avian influenza "seed" vaccine.** If unchecked, H5N1, or avian flu, has the potential to kill untold millions of people. St. Jude provided the National Institute of Allergy and Infectious Diseases (NIAID)

with "seed" material that can be used by the U.S. government to develop a commercial vaccine. The GMP will also provide NIAID with seed vaccines for variants of H5N1.

- **HIV vaccine** designed to protect individuals against all variants of the virus that causes AIDS. Phase I trials of this three-part vaccine are underway, and the GMP will produce all components for follow-up clinical trials.
- **Parainfluenza, or croup vaccine.** Phase I trials were completed last year, and the GMP is providing new vaccine for further clinical trials.
- **Monoclonal antibody to treat neuroblastoma,** a nerve cancer. This antibody is modified to make it more effective than other antibody treatments, while reducing painful side effects.
- **Gene therapy for hemophilia B,** a severe bleeding disorder. The treatment will use a genetically modified virus that will carry the gene for Factor IX, a protein critical for clotting.
- **Cholera vaccine.** More than 2.5 million people around the world die of cholera each year. Clinical trials are underway to study the safety and efficacy of the St. Jude vaccine.

Thanks to donor support, St. Jude is the world's only pediatric cancer research center to have an on-site facility to produce products such as these. It's an investment that will pay dividends in lives that are saved. ●

BY MARC KUSINITZ, PhD



# PepperPower

*Survivor* star Jeff Probst teams with Chili's to support St. Jude.

BY JOE HANNA

**O**n September 26, 2004, Chili's Grill & Bar put the finishing touches on its Create a Pepper to Fight Childhood Cancer campaign. The national event, featuring Jeff Probst, host of the Emmy-Award winning television show *Survivor*, would go on to raise \$2.5 million for St. Jude Children's Research Hospital.

That same day, Shiloh Carroll and her family walked through the doors of St. Jude for the first time. Shiloh had a brain tumor called medulloblastoma, and her family wanted her to have the best chance of beating the disease.

Fast forward to April 18, 2005. Shiloh sits in a chair in the hospital lobby, talking with Probst, who is once again spokesperson for the Chili's Create a Pepper to Fight Childhood Cancer program. Shiloh and patient D'Avalon Randolph are assisting with some of the video work. Probst plops down in a cushioned chair, conversing with the patients and challenging them to guess each other's birthdays.

Probst hopes his support can help Chili's again—and help children like D'Avalon and Shiloh.

"Chili's has been gracious enough

to create a cool program and invite me to be a part of it," Probst says when he's not filming or goofing around with patients. "They had this event for the first time last year, and I think the success of it surprised everyone. So they decided to do it again."

The Chili's program has a simple premise: throughout September, patrons can pay \$1 (or more) to color pinups of the restaurant's signature Chili pepper. The pinups are then displayed on the restaurant walls. In addition, Chili's donates all profits one day that month to St. Jude.

St. Jude patient Ali Mills participated with Probst on the

Chili's fund-raiser last year, joining him for a photo shoot and dining with him at a Memphis-area Chili's. They also participated in joint television interviews conducted from the hospital via satellite with stations nationwide. The two became good friends. But in April 2005, Ali lost her battle after several years of fighting neuroblastoma, a cancer of the nervous system.

Two days after her funeral, Probst is once again at St. Jude. But, he says, it is not bittersweet. "When I think of Ali, I smile," he says. "Ali changed more lives in her 13 years than all the people I know combined. She had a bigger impact.

"You know," he goes on, "life is what it is. That's the message I got from Ali. And you have to live it. Anyone not living it is a fool and is wasting the gift of life."

Chili's hopes to raise \$3 million this year so that children around the world can have that gift of life.

"All of us at Chili's were extremely pleased with the inaugural results of our national partnership with St. Jude," says Kevin Carroll, Chili's regional vice president. "We know that while survival rates are climbing, children still lose their lives. We felt that very personal sense of loss with the passing of Ali, who we were so fortunate to get to know during our 2004 campaign. There is still work to be done, and we're fully committed to helping the team here at St. Jude, which is why we intend to make this year's promotion even more successful."●

**Jeff Probst makes new friends through his affiliation with St. Jude and Chili's Grill & Bar.**

## A Perfect Match

BY BETH MCGOWAN



Wayne Speer, PhD, and his wife, Daveen, inspire others to help save the lives of St. Jude patients and support research that is shared around the globe.

### One couple finds love and inspiration through St. Jude.

**W**hile vacationing in Morocco more than six years ago, Wayne Speer, PhD, found that his long association as a St. Jude volunteer, fund-raiser and donor brought a gift to him. Wayne met his wife, Daveen, when one of her daughters noticed a St. Jude sticker on his suitcase and started a conversation with him. Daveen's daughter had participated in the St. Jude Math-A-Thon program at her school, and the two talked about their mutual interest in the hospital. This chance meeting led to an introduction to her mother followed by a whirlwind courtship and marriage five months later.

"St. Jude brought us together," Daveen says. "We've been together ever since, continuing to support this great cause as a team."

Wayne became involved with St. Jude in 1968, when he worked in

downtown Memphis. "I had heard of St. Jude and wanted to see for myself what the hospital was all about," recalls Wayne, CEO of Shirlo Inc. "When I saw the children, I was hooked. St. Jude was an amazing place."

Soon after that visit, he began his long-term volunteer service with the hospital.

"I played Santa Claus and took the children to the circus, then eventually was able to participate in financial ways as well," he explains. "I like to think that our contributions have made a real difference in these children's lives."

Grateful that their own children are healthy, the Speers continue to help other children who are not so fortunate. Many of the couple's five daughters, eight grandchildren and one great-grandchild also participate in raising funds for St. Jude.

As self-described goodwill ambassadors for St. Jude, the Speers inspire others to become involved in helping save the lives of St. Jude patients and supporting research that is shared around the globe. Recently, the couple raised funds for the hospital by sponsoring a challenge grant, where they donated a large sum to the hospital, then challenged other donors to match their gift.

Wayne co-founded the Memphis Club, which consists of influential businessmen and women who are focused on supporting St. Jude. They also sponsored the Gift Planning Luncheon this year so that donors who remember the hospital through their legacies and with life-income gifts could participate in a special event at St. Jude.

The number of ways the Speers contribute to the hospital continues to grow. When another of Daveen's daughters chaired the "Fitness for a Cure" fund-raising program in New Hampshire, the Speers were there with her as sponsors of the event, which raised \$172,000 for the hospital. "I've always tried to promote volunteerism with my family, my employees, my friends and others who are influential in raising awareness of the wonderful work done by St. Jude," says Wayne. "It's all for the children."

"It's so easy to become involved with St. Jude," says Daveen. "If every person would tell one other person about the hospital's mission, what a difference that would make. We have been fortunate to introduce many others to the miracles that occur at this special hospital for children diagnosed with cancer and other catastrophic diseases. We look forward to continuing our support by encouraging others to do the same."

*To learn about more ways to give, call ALSAC Gift Planning at (901) 578-2425 or toll free at (800) 830-8119, ext. 2425.●*



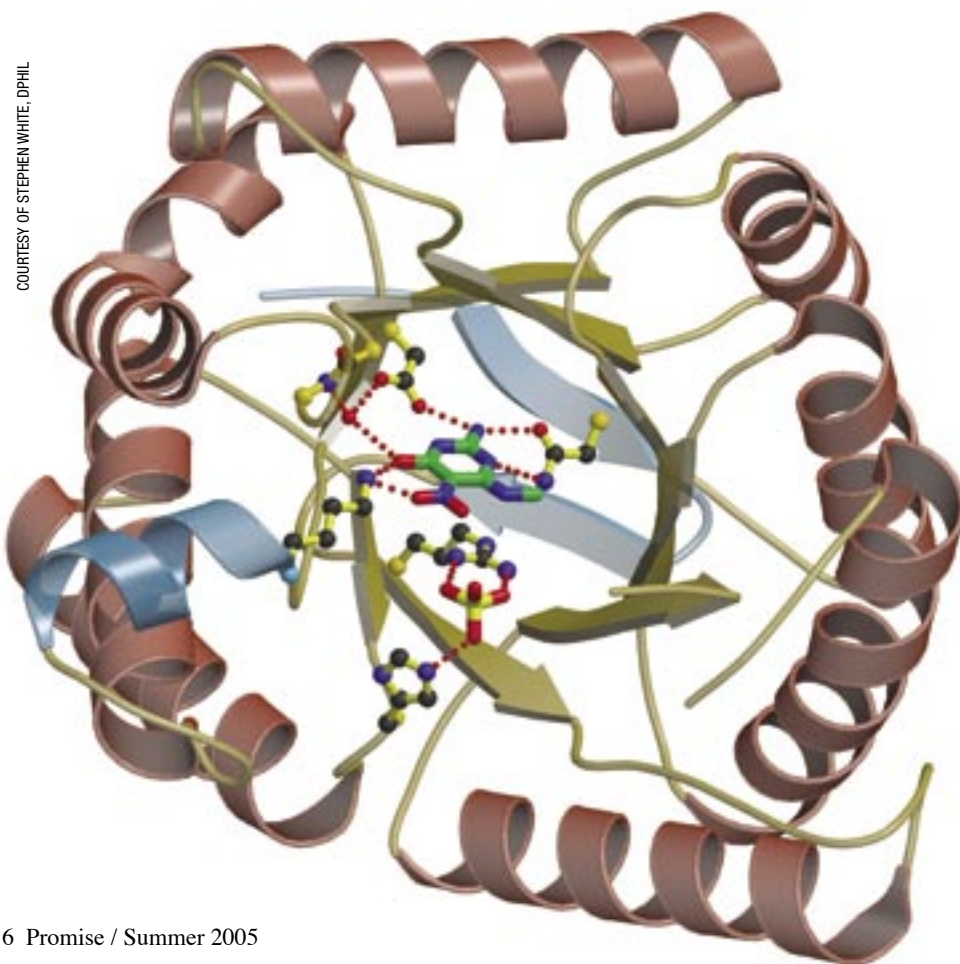
# ABondingExperiment

BY TANUJA COLETTA

## Researchers find ways to sabotage the schemes of bacterial invaders.

**A potent inhibiting molecule called Manic may hold the key to thwarting the bioterrorism agent anthrax.**

COURTESY OF STEPHEN WHITE, DPHIL



By the end of most James Bond films, the super-suave secret agent has foiled some evil villain's plot to inflict havoc on the universe. Armed with a myriad of snazzy gadgets and his infallible smarts, the spy outwits opponents skilled at resisting capture.

Researchers at St. Jude Children's Research Hospital know these types of villains all too well.

For children with diseases like cancer, infection-causing bacteria are scarier than any movie monster. Cancer treatments often leave patients with weakened immune systems, so bacteria that may land an otherwise

healthy person in bed for a few days can leave St. Jude patients desperately hanging onto their lives. To make matters worse, these microorganisms have proven adept at altering themselves to resist many antibacterial drugs, leading researchers to continually search for new modes of attack.

Unlike 007, St. Jude scientists find that fighting catastrophic diseases is no task for a solo adventurer. Chemists, biologists and virologists collaborate through the hospital's Small-Molecule Therapeutics Program to discover ways of sabotaging crucial systems in bacteria and other pathogens. Investigators from Infectious Diseases, Biochemistry, Structural Biology, Pathology, Molecular Pharmacology and Medicinal Chemistry are finding targets for new drugs so that children have the upper hand when fending off bacterial invaders.

### Serious stuff

St. Jude researchers hope to combat this huge problem with small molecules that could derail the normal protein functions in pathogenic bacteria. "Finding the right type of chemical monkey wrench is crucial to overcoming drug-resistant bacteria," says Charles Rock, PhD, of Infectious Diseases. "This is serious stuff. Bacteria have evolved mechanisms to defeat the available antibiotics. St. Jude is interested in tackling this problem because our kids have compromised immune systems, but this is really a national issue."

Rock and his colleagues are searching for molecules that can fit onto the surfaces of proteins like locks and keys. Once they infiltrate the bacteria, these undercover imposters modify the bacteria's metabo-

SETH DIXON



**"This is really a story of how basic science can do good," says Charles Rock, PhD, of St. Jude Infectious Diseases. "We are not going to get the therapeutics we need for these childhood diseases unless we go after these discoveries ourselves."**

lism and bring their dreadful plans to a grinding halt.

Stephen White, DPhil, chair of the St. Jude Structural Biology department, uses sophisticated software to understand how proteins are constructed and where small molecules could fit. "We're looking for drugs to inhibit these protein molecules, and we're looking at the method by which proteins interact with each other and with DNA so we can thwart them," he says.

### Seasoned sleuth

In his study of bacteria, Rock specifically looks for systems that are not duplicated in humans. "That way, if we knock the bacterial system out, it doesn't affect us," he says. "For example, penicillin knocks out one of the mechanisms whereby bacteria make their cell walls. Well, we don't have those enzymes, so it doesn't affect us and there are minimal side effects. The idea is to poison the bacteria, not poison the person."

With the patience of a seasoned sleuth, Rock has unraveled the cascades of biochemical reactions in bacteria that control the production of fatty acids. "When we began these studies 25 years ago, we were just trying to understand

how things worked," he says. "Over the years, I've been able to discover two key factors—bacteria must make fatty acids or they die, and this process is different from the human system." While bacteria have evolved resistance to other antibacterial drugs, bacterial fatty acid synthesis is a new target that resistant organisms have not encountered.

"So now we have something that's absolutely essential for the life of the bacteria that is clearly different from what is in humans," Rock says. "This is the fundamental target profile for developing drugs."

### Artful swap

Like Vincent van Gogh, Stephen White produces colorful, swirling 3-D images to give scientists blueprints of protein structures. But while the artist painted night skies and sunflowers, the structural biologist's subject is much more serious—the bioterrorism agent anthrax.

White is studying how slight mutations in the structure of a crucial anthrax bacterium enzyme called DHPS can make the pathogen resistant to antibiotics called sulfa drugs. If not for this resistance, sulfa drugs could be used to treat patients with

infectious diseases. The antibiotic targets bacteria's ability to produce folic acid, which is essential for making DNA. White and his team are studying new ways to disrupt this process in anthrax.

"Bacteria have to make folate from scratch," White says. "Humans get it from our diet. So it's the perfect pathway. If we can kill the enzyme, the bacteria don't make folate, don't make DNA and die."

Sulfa drugs work by binding to DHPS, rendering it ineffective. Now that bacteria have found ways to work around this dead end, White's team has discovered a potent inhibiting molecule called Manic, which fits onto the enzyme. Because most infectious bacteria use DHPS to make folate, the St. Jude findings hold promise for solving the problem of antibiotic resistance among microorganisms causing tuberculosis and pneumonia, as well as potential bioterrorism agents.

### Mission possible

The next move is to translate these discoveries into drugs. To do that, St. Jude scientists are using powerful robots to search thousands of molecular compounds for ones that are both powerful and well-tolerated in the body. The hospital's new Chemical Biology and Therapeutics program will dramatically boost this capability and provide an important new dimension to the hospital's battle against childhood diseases.

"This is really a story of how basic science can do good," Rock says. "Treatments for catastrophic childhood diseases are not cash cows for big pharmaceutical companies, so our kids are basically an orphan population of patients. That's why it's important for St. Jude to think about these things. We are not going to get the therapeutics we need for these childhood diseases unless we go after these discoveries ourselves."

It doesn't take James Bond to figure out why families count on St. Jude researchers to put away the bad guys and allow their children to set out on all the other adventures life has in store. ●



# No Stone UNTURNED

BY VICTORIA TILNEY McDONOUGH

## St. Jude rolls out its bold, new palliative care initiative.

When Jack Pavlat held his daughter for the first time, feeling her little starfish fingers wrap around his thumb, he knew why he had been put on earth. One glimpse of his beautiful little Suzanne, and his world changed forever.

His world changed again when he and his wife, Barbara, learned that their 3-year-old daughter had stage IV neuroblastoma, a cancer that affects the sympathetic nervous system. More than eight years later, in 2001, they lost Suzanne to her disease. But even now, living on this new landscape without their precious girl, the Pavlats know they wouldn't have changed a thing—not how they helped Suzanne live her life nor how they let her say goodbye.

For several years, the Pavlats have returned to St. Jude Children's Research Hospital to volunteer as night managers at Ronald McDonald House, where some families live while their children are in treatment.

"It's our way of paying St. Jude back for all the love and care they gave Suzy and us," Jack says. "From the minute we arrived here, when Suzy was 9, St. Jude took care of us—from giving Suzy the best possible treatments and minimizing her suffering to helping all three of us live fully and joyfully."

### New definitions

At St. Jude, alleviating the pain and suffering of patients and families is the goal. That can mean treating a tumor in hopes for a cure. It can mean helping a child learn to walk with a prosthetic leg. It can also mean helping families find ways to stay close, laugh and navigate challenges together.

"At St. Jude, we stretch the definition of palliative care," explains Pam Hinds, RN, PhD, director of Nursing Research. "We don't mean

just end-of-life care. What we mean is care from the moment of diagnosis of a potentially life-threatening illness until cure or until end of life—care that will better position the child and family for the best possible outcomes. More specifically, we mean care that seeks to prevent, relieve, reduce or soothe the symptoms produced by serious medical conditions or their treatment and to maintain patients' quality of life."

For many years, Hinds and a devoted task force have conducted studies that explore how to reduce the physical and spiritual suffering of patients, their families and staff no matter the outcome. All of this work is applied in a new St. Jude initiative called Preventing Symptoms and Suffering from Diagnosis Forward, an effort that will ultimately have its own designated staff.

Research to discover how best to approach palliative and end-of-life care for patients, families and employees is already up and running. St. Jude studies address coping skills, end-of-life options and symptoms, the importance of avoiding "care hand-offs" and how best to implement a parent's internal definition of a good parent. This work will result in educational materials for parents and staff as well as guidelines employees can use when caring for patients.

"More than anything else, patients and those who care for them fear pain and suffering," says Chaplain Brent Powell. "The palliative care initiative offers us a stable base of organized methodology

SETH DIXON



St. Jude nurse Allison Worthington and patient Parker Deason know that hugs are an essential part of treatment.

### Navigating with grace

Robert Rydell counts his blessings when he watches his 14-year-old son, Brayden, play baseball and whoop it up with his friends. Brayden discovered he had acute lymphoblastic leukemia and acute myeloid leukemia New Year's Day 1999. Almost three years have passed since his second bone marrow transplant.

Brayden's dad believes the "whole person/whole-family" care at St. Jude made all the difference.

"Brayden is naturally a very strong and positive kid. He lives his life fully; he doesn't center it around his disease," Robert says. "Cancer treatment can be so rigorous, so regimented, but in the middle of it all, Brayden was always kept busy and involved at St. Jude with fun activities so he could remember that he was still just a kid. There is so much to be said for that."

Robert also emphasizes the importance of being involved in every decision.

"For us, information is key; it relieves stress," he says. "You can never be prepared for this in your life; learning your child has cancer is catastrophic. But it is a relief to understand the illness and what the doctors are looking for and aiming at. Information—and being a part of the team—helps you keep it together. It made all the difference for Brayden, and for our whole family."●

from which we can address these issues from physical, emotional and spiritual perspectives."

### Life's little moments

Although Suzanne was only given a 10 percent chance of surviving, the Pavlats never gave up hope. "We always continued forward with the assumption that Suzy would live. And we tried to make life for her as full and fun as possible. She was still a little girl, after all," says her dad.

St. Jude helped the Pavlats achieve this for Suzanne. The School Program worked with her teachers back home so she could keep up with her classmates and take all the state tests, just like any other elementary school kid.

St. Jude employees helped the family find a local horse stable so Suzanne could take riding lessons, something she had always dreamed of doing. Two St. Jude nurses even took Suzanne on a Girl Scout camping trip. "Those two nights were the only two she wasn't with us. She loved it," says Jack. "They went to a red clay mud slide and swam and played. That

weekend, she was just like any other 10-year-old." Jack adds how grateful he is to St. Jude staff for the emotional support; it has made all the difference during their journey.

The Palliative and End of Life Care Task Force involves parents—and children, when age appropriate—in the decision-making process from the moment they arrive at St. Jude. "For each family, we want to create an environment where everyone can put an idea on the table to benefit the child and family then cull these options into a team approach," says Hinds. "This team, of course, includes the family and the child, as desired."

"I never felt like a mushroom; never felt left in the dark," says Jack. "Whenever we sat down with our doctors, they were honest with us. They might give us bad news, but they also gave us hope and the confidence to make decisions and move forward. It meant a great deal to us that Suzanne was always a part of what was going on. Decisions we made as a team had Suzy's best interests at the forefront."



"From the minute we arrived here, St. Jude took care of us," says Jack Pavlat, pictured with his wife, Barbara, and their daughter, Suzanne.

DALE HAWKINS





Paige Malone watches cartoons on a TV monitor while her mother, Tamara, talks to Beverly Fletcher, RN. St. Jude researchers are looking for ways to reduce stress in patients and parents.

# Sidestepping Stress

BY TANUJA COLETTA

## Easing parents' anxieties could make recovery smoother for patients.

**W**hen Paige Malone giggles, her whole body giggles. Her cheeks bounce, and laughter tap-dances off her tongue. Even the ringlets atop her head groove to her good time.

The 7-year-old is a natural performer. She initially feigns shyness until she extracts the right amount of coaxing from her mother. When she can no longer ignore the urge to dance, Paige wiggles her two-foot frame to whatever radio song pops into her head and curtsies when her audience breaks into cheerful applause.

Tamara Malone is happy coaxing her daughter to dance. Two years ago Paige was so weak from leukemia treatments that Tamara pleaded with Paige to hang onto life. The mother of three, Tamara can hardly measure the amount of stress she's been under for the past two years watching her middle child endure radiation, chemotherapy and two bone marrow transplants. "It was a lot to take," Tamara says. "You just pray that you'll make it through."

Psychologists at St. Jude Children's Research Hospital are studying parents like Tamara to predict those who are at high risk for increased distress when their children undergo stem cell or bone marrow transplants. Caregivers can help these mothers and fathers find ways to cope with stress, making recovery a smoother process for young patients.

### Back and forth

Tamara Malone remembers everything about the day her world turned upside down. To say she was stressed is an understatement. On June 5, 2003, Tamara took Paige to the doctor after noticing bruises on her arms and head. A blood test revealed that Paige had acute lymphoblastic leukemia (ALL), the most common childhood cancer. She was referred immediately to St. Jude.

"I was so nervous," Tamara recalls. "I was thinking the whole way from the pediatrician's office to the hospital, 'Oh my God, what is happening?' My whole family was already at St. Jude waiting for us when we arrived."

Nineteen days of chemotherapy failed to rid Paige's body of leukemia cells. Doctors told Tamara her daughter would need a bone marrow transplant, a procedure to replace the tissue that produces blood cells.

"I panicked at first because I thought this was going to be some kind of major surgery," Tamara says. "I had so many questions running through my head. What if we don't find a donor? How much can her body take? But I calmed down after talking to the nurses. I realized that St. Jude has been really

successful in treating ALL. And it turned out that her father could be the bone marrow donor."

Although the side effects and experiences during stem cell and bone marrow transplants vary from child to child, patients typically stay in or near the hospital for 100 days and are monitored closely for signs of negative reactions, such as graft-vs.-host disease and infections.

Paige made it through the transplant with flying colors, avoiding complications or infections. However, eight months later, Paige turned pale and lethargic. She had relapsed.

"I was at a standstill," Tamara says. "I couldn't believe it. It's like we were on a yo-yo going back and forth." This is when her stress level hit the roof. "Being the mother of three girls is stressful under normal circumstances because they have school, Girl Scouts and other activities," she says. "Cancer doesn't happen in a bubble; life goes on around you. We still had bills to pay, chores to do and a family to run." Paige's father juggled work and the other daughters, while Tamara spent nights with Paige in the hospital getting ready for her second bone marrow transplant.

Again, Paige endured the procedure like a champion, Tamara says. "She'll be one year out of transplant in August, and she's doing great."

The same can be said for Tamara. She learned how to cope with stress after taking part in a St. Jude study that tracked parents of children undergoing bone marrow and stem cell transplants. Tamara was part of a group that received interventions like massages, CDs with relaxing ocean sounds and advice for coping with stress. "As the mother, you always put yourself last," Tamara says. "But at St. Jude I learned that by taking some time out for myself, I could help Paige even more because she wouldn't see me stressed out all the time."

### Moving forward

Stressed parents can lead to stressed kids, according to clinical psychologist Sean Phipps, PhD, of St. Jude Behavioral Medicine. "The research suggests that if you have highly stressed parents, this is very likely to impact the coping and adjustment of the child," he says. "So understanding what parents are going through, and on some level intervening with parents to reduce their stress, might in some cases actually be more practical than intervening with the child."

Phipps has led a five-year study funded by the National Cancer Institute to study stress in families of patients undergoing bone marrow and stem cell transplants.





Transplant patients were chosen mainly because the procedure is a predictable source of stress as opposed to events like hurricanes, tornadoes and car accidents. “With transplants, you generally know when it’s going to happen, and we can study people before and after it happens,” Phipps says. “Also, we know that this is a group at our hospital that experiences some of the most intense, acute, prolonged stress and is likely to be in more need of help.”

The researchers studied 151 parents and guardians by using psychological tests that measure parental stress and moods; child behavior problems; coping; and other factors that, together, identified parents at higher risk for distress. The findings showed that parents were especially likely to suffer significant distress if both they and their children had previous difficulties coping with illness-related stress and if the children had problems cooperating with their parents.

Parents of sicker children appeared to be more likely to suffer greater distress than parents of children who were not as ill. In addition, parents without strong family support networks suffered more distress, as did those parents who were less expressive and tended to cope with difficult situations by avoiding them.

“You have some parents who naturally take an active approach to dealing with stress—they get on the Internet to read about the disease and treatment; they join support groups; they talk to other parents,” Phipps says. “Other parents want to put it out of their minds; they say they will leave it in the doctors’ hands. It’s not to say that avoidance is always bad, but folks who do this generally have the greatest distress.”

Phipps’ team concluded that the most effective way to assess parents at higher risk for increased distress is to focus on past illnesses and treatment-related issues of the children rather than on broader aspects of parental and child behavior. “You can do lots of fancy personality tests, but we found that really the germane predictor was simply to ask parents specifically how they have coped with their child’s illness in the past,” Phipps says. Based on the answer, caregivers can determine measures that should be taken to help parents reduce transplant-related stress.

Phipps and his colleagues found that eventually most of the acute distress associated with transplants resolves in both parents and patients. The researchers are now interested in finding any long-term effects. “For example, one of the hot topics these days is post-traumatic stress disorder,” Phipps explains. “We want to

know if there is an element of the stress that will rear its ugly head later on. If so, maybe we can help parents make adjustments now for down the road.”

### Giving strength

While Tamara concedes that stress will probably always be a part of her life, she says she now knows how to deal with it. “I know that as a parent, sometimes the best thing you can do for your child is to take care of yourself,” she says. “I’ve learned a lot from Paige. Never seeing her get down has been an inspiration to me.”

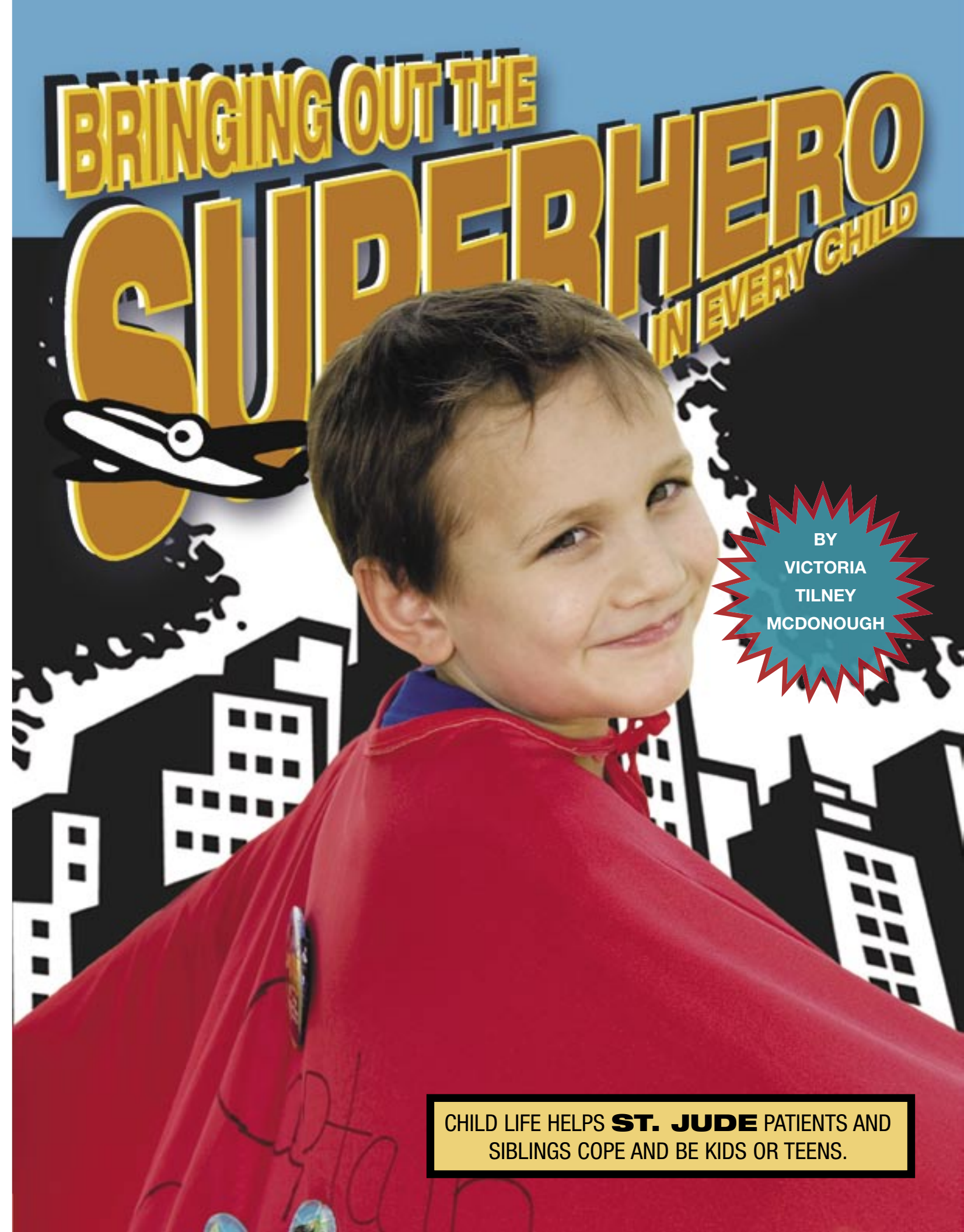
What little Paige remembers of the transplants is that it was a happy time when she got to color pictures for her hospital room and play with other kids. She’s too busy planning her future to dwell on the past.

“When I grow up I want to be a lawyer, an artist, a psychiatrist, a doctor—to help the kids of St. Jude—a cheerleader, a teacher, a judge, a tutor and a singer,” she says before pausing for a moment and tapping her index finger to her chin. “Oh yeah, and I want to dance.”●



Paige Malone (left) has no time for stress as she and her older sister Taylor play their way through Paige’s leukemia treatments. The girls are pictured here in 2003.

LAURA HAMR





**W**ith pomp and circumstance, Angie Koeneker presents the colorful sticker.

“Captain Cooperation, for holding still during your blood draw, you have earned this medal!” Ceremoniously, she places the “medal” on the superhero’s small cape. Grinning, 5-year-old Landon Brereton twists his cape around to admire his latest medal of honor. Everyone cheers; his parents and nurses smile with pride and relief.

Before Koeneker presented the young patient with his cape—transforming the small boy into a powerful superhero—Landon had barely been able to pass through the front door of St. Jude Children’s Research Hospital without crying.

“He was having a really tough time coming here. Even the parking lot upset him. He was scared and anxious, plus he felt awful. The nurses had difficulty assessing him,” says Koeneker, a Child Life specialist.

After discovering that the little guy liked superheroes, Koeneker bought him a cape and, across the back, wrote “Captain Cooperation” in big, emphatic letters.

“His nurses and I gave it to him and explained that he didn’t have to be happy when he came to the hospital but, being a superhero, he’d have to use his powers to help the doctors and nurses try to help his body get better. Every time Landon cooperated, he would earn a new sticker—a new medal of honor,” she says. “Our ‘captain’ was able to use his cape as a way to cope with what he was going through at St. Jude until he didn’t need it anymore.”

### Tools of the trade

The superhero cape is just one of the tools Child Life specialists might use to help St. Jude patients and their siblings overcome anxiety and understand medical procedures. Child Life experts assess the needs of each child and teen and then provide services that help nurture the child by focusing on strengths,

**CAPTAIN COOPERATION, FOR HOLDING STILL DURING YOUR BLOOD DRAW, YOU HAVE EARNED THIS MEDAL!**



**Spiderman had better watch out; patient Landon Brereton, also known as “Captain Cooperation,” has earned many medals for bravery. In 2002, Child Life Specialist Angie Koeneker created the superhero cape to help Landon deal with being a St. Jude patient. Although he no longer needs the cape when going through treatments or procedures, Landon occasionally wears it to remind himself of his special powers.**

encouraging normal life experiences and increasing coping skills.

“Sometimes the kids are angry or frustrated. They get tired of their treatment; they miss home, their normal lives,” explains Child Life Specialist Shawn Brasher, who works with patients undergoing stem cell transplants and their siblings, whose lives are also disrupted.

Therapeutic art activities can work wonders to help children express their feelings on their own terms. “One art project we did was to decorate plastic urinals with pictures and words showing stuff we were sick and tired of. Then we set them up like bowling pins and knocked them over,” he says.

Brasher and the other Child Life specialists also use stuffed dolls for medical

play to teach patients and siblings about procedures and treatments. Letting children practice putting in central lines or inserting IVs helps them understand what happens and also allows for the release of feelings.

### The little things

Inpatient Child Life Specialist Amy Kennedy attends medical rounds each morning to share medical and psychosocial information about “her” patients and families. “The more I can learn and know about my kids and their families, the more I can support their adjustment,” she says.

“If I can make an impact—make life a little less scary, a little more fun and normal for my patients, their siblings and their families—then it’s all worth it,” Kennedy says. “Even by doing little things.”

Those small details seem to make all the difference: simple actions such as helping a boy in the ICU make a birthday bag for his sister, arranging for a patient to spend a week at summer camp or racing silly, mechanical wind-up brains to elicit laughs. These “little” things can help buoy a child’s spirits and sense of self.

The big things are, of course, crucial, too. “We had one boy who thought he gave his brother cancer by pushing him down,” explains Crystal Rust of Child Life. “No matter what you’re explaining, you have to use concrete language: ‘There is a lump of sick cells in your brother’s body that shouldn’t be there. It’s called a tumor, and it’s no one’s fault. There is nothing that you or your brother said or did that made this happen.’”

Child Life specialists might read a book or do a workbook with such a child

to help him express his internalized feelings. Or they might arrange to tour the lab to show him the “sick cells” on the X-rays or scans.

For teen patients and their siblings, the Teen Room is a refuge away from parents, doctors and other grown-ups.

“We have ‘Coffee Talk’ just for teens to talk and share their feelings,” says Clare Gardner of Child Life. “One meeting sparked a conversation between a patient and another patient’s sibling. The sibling explained how hard it can be as the sister of a cancer patient: how she felt left out, pushed to the side, while at the same time she was worried and was unable to concentrate in school. The patient said she hated that her sisters were jealous of her because she gets so much attention. She didn’t want all this attention, she said, she just wanted to be normal like them. This exchange happened naturally; I think they both left with a new understanding.”

### Head and heart

Child Life employees keep in touch even when patients go home. “If a child is at home with hospice, for example, we want them to know that they are not forgotten—that they are still in our hearts. Therefore, we keep in contact with them along with staff from their primary clinic. Every couple of days, we send them special cards that everyone on their team signs,” Koeneker says. “We’ve heard that these have meant a lot to the kids and their families. Some kids can’t wait to check the mail each day, or they’ll keep the cards by their bed to remember how many people here love and miss them.”

Child Life specialists also send letters and resource-

es to siblings at home so they understand what’s going on with their brother or sister at St. Jude, and so they don’t feel left out or unimportant.

Whether they’re helping a child or teen develop coping strategies or create “legacy” art work, Child Life specialists work in collaboration with the rest of a patient’s St. Jude team.

“Often, parents ask to see Child Life when we are trying to resolve a stressful situation for the child,” explains Carlos Rodriguez-Galindo, MD, Hematology-Oncology. “For example, my little kids with retinoblastoma have to undergo multiple eye exams under anesthesia. Most of them panic with the thought of eye drops

or the anesthetic gas. This is a very stressful situation for the children and their parents, which recurs every few weeks. Raye [Pietruzska] and Crystal [Rust] know these children very well; they are always with them in clinic or upstairs before they undergo these procedures.

“At first, I remember that it almost hurt my feelings that the parents and kids kept asking for Child Life; you know, I—the doctor—was right there, trying to be supportive and take care of the problem ....” He smiles and adds, “but you get used to it. Actually, I rely so much on them that I am now the one who calls for help.” ●

**SOMETIMES THE KIDS ARE ANGRY OR FRUSTRATED. THEY GET TIRED OF THEIR TREATMENT; THEY MISS HOME, THEIR NORMAL LIVES.**



**Child Life Specialist Shawn Brasher understands the power of creating art—whether it’s just for fun or to help patients or siblings communicate without the need for words. Here, Brasher helps 6-year-old Christopher Felix paint a mask to address his feelings about undergoing a stem cell transplant.**





# Caitlyn's Comforts

BY CARRIE L. STREHLAU

Sometimes it's the little things that make a difference—a mom who cuts her hair to show solidarity; a medical team that fosters a girl's sense of humor; a positive hospital “family.”

Caitlyn Mathis stares at her reflection in the mirror. Her thinning hair is barely visible on her head. “What will kids say?” she nervously asks. “Yes, some kids may pick on you, but they don't understand,” responds her mother, Cynthia Mathis. “I'll cut mine short if it will help.”

Caitlyn laughs. That afternoon the sight of Cynthia, with a newly shorn head, makes her daughter laugh again. “You really did it!” Caitlyn says, beaming.

The mother-daughter pair are accustomed to supporting each other no matter what. Now a spunky 8-year-old, Caitlyn was 6 when she found out that she had a tumor called an immature teratoma in one of her ovaries.

“She looked six months pregnant,” recalls her mother. “She was complaining of stomach pains, and I noticed that her belly was larger some days more than others. We went to the doctor, who said to observe her. On the next visit, I brought measurements of her belly I had taken in the course of the week.”

Doctors ran tests on Caitlyn to determine the cause of her abdominal growth. Scans showed the cause of Caitlyn's stomach pain and distended abdomen was a tumor—the size of a chicken egg—growing inside her body. The doctors immediately sent the young patient from her hometown to a nearby hospital for CT and MRI scans.

“We got the same answers,” Cynthia says. “It was a large tumor in her ovary, but the hospital was not equipped to handle the case.” Caitlyn was then transported to another hospital. “By that time I was devastated because I was not quite sure what Caitlyn had or why she had it,” Cynthia continues.

Several more tests that evening confirmed Caitlyn had a malignant germ cell tumor that required an immediate operation and removal of an ovary.

“I went into the hallway and cried,” Cynthia says. “I had so many questions. But I pulled myself together to talk to Caitlyn. I didn't want to keep anything from her.”

The mother and daughter sat in the hospital room talking about the operation that would change their lives.

“I wanted to cry,” Caitlyn recalls. “It was hurtful to know I had a tumor. But my mom helped me a lot that day.”

According to Cynthia, Caitlyn gave her strength. “She's stronger than I am,” Cynthia says. “She said, ‘Mom, it's gonna be all right. God will bring me through.’”

The next day, surgeons removed the large, malignant tumor from Caitlyn's abdomen but determined it was too risky to remove the many small tumors sprinkled over the surfaces of her intestines and liver. After the operation, the doctors sent Caitlyn to St. Jude Children's Research Hospital.

## Teamwork and laughter

“When she arrived, we gave her four courses of chemotherapy right away,” says Sheri Spunt, MD, Hematology-Oncology. “The particular germ cell tumor she has is not unusual. What is unusual is how widespread it is, and that all of it can't be removed.”

*“I was scared at first. But I was happy because the doctors were right there, and I knew they would take care of me.”*

As chemotherapy treatments began, Spunt and her colleagues kept Caitlyn in the loop every step of the way.

“I was scared at first,” Caitlyn says. “But I was happy because the doctors were right there, and I knew they would take care of me.”

Four months of chemotherapy left Caitlyn tired, weak and bald.

“I didn't want to lose my hair, but I thought, ‘My hair or my life,’” Caitlyn says. “When my mom cut her hair, we [Cynthia, Caitlyn and older sister, Tiffany] were triplets because we all had short hair.”

“I knew I couldn't make her cancer go away, but I could make her life, for one day, very special,” Cynthia adds.

All of the treatments and complications never dampened Caitlyn's spirit.

“We are always laughing when we're with her,” Spunt says. “She is so funny and so full of energy—and she always has a story to tell you.”

The laughter kept Caitlyn and her mother going as they traveled back and forth to St. Jude for appointments and

tried to keep home life as normal as possible. Caitlyn continued attending school in her hometown and even played basketball, soccer and baseball on her better days.

“I kept a close eye on her, but it was important to me that she be a kid,” Cynthia says. “Some kids who didn't know her thought they could catch cancer, but she was great at dealing with them. She is mature beyond her years.”

Aaron Weiss, DO, St. Jude Hematology-Oncology fellow, recognized Caitlyn's maturity early on, and he says it helped her throughout her treatment.

“Caitlyn is different from most kids her age,” he says. “What stands out most is her infectious personality and laughter; yet, she possesses an amazingly mature ability to comprehend serious and complicated matters. That made it easier for us to speak openly with her about treatment-related issues.”

But even a mature child gets excited at the chance to go to Disney World. “Me, my mother, sister and grandmother went to Florida together,” Caitlyn says. “I got



Aaron Weiss, DO, of Hematology-Oncology shares a laugh with Caitlyn Mathis during an exam.





Even when she was hospitalized, Caitlyn managed to eke out a smile for her family, her caregivers and even celebrities visiting the hospital. Here, she mugs for the camera with country music artist Kellie Coffey. “Caitlyn is different from most kids her age,” observes Aaron Weiss, DO, St. Jude Hematology-Oncology fellow. “What stands out most is her infectious personality and laughter; yet, she possesses an amazingly mature ability to comprehend serious and complicated matters.”

to meet Mickey and Goofy and got to get wet in the water park. I really want to go back.”

### Keeping a close watch

Thus far, the tumors left after chemotherapy inside Caitlyn’s young body have remained benign. Her treatment team at St. Jude is watching those tumors closely.

“Unfortunately, although Caitlyn responded well to chemotherapy, she still has a lot of tumor left within her abdomen that is benign and still too extensive for surgery to remove,” Spunt says. “This benign tumor can become cancerous at any time, but the likelihood that it will happen is unknown.”

If cancer does develop again, Caitlyn will receive more chemotherapy, and her treatment team will weigh the risks and advantages of another operation.

“Currently, she is not receiving any treatment, but we do continue to follow her every few months,” Weiss says. “We take scans of her abdomen and check cer-

*“Many people underestimate what kids can handle. Caitlyn trusted us, and she knew we were all on the same team to help her get better.”*

tain blood levels. At this point, she has no signs of cancer.”

The further from diagnosis she is—assuming that the tumors do not change—the less frequently Caitlyn may need to be checked. “Unfortunately, even as we spread out her visits, Caitlyn will need to be followed indefinitely, long after she leaves St. Jude,” Weiss adds.

Although Caitlyn may face a lifetime of doctor’s visits to check her tumors, Cynthia knows her daughter will remain positive. “It just amazes me to look at her and know what she’s been through,” Cynthia says. “She has such an open heart and high spirits about life—and she never gave up.”

Her doctors agree. “Many people underestimate what kids can handle,” Spunt says. “Caitlyn trusted us, and she knew we were all on the same team to help her get better.”

To ask Caitlyn, her family at home and her family at St. Jude were and continue to be her source of encouragement and strength.

“The doctors are my favorite people at St. Jude,” she says. “They helped me get through my treatment, and they always make me laugh. It’s a special thing that makes them funny. I am thankful.” ●

# 1 in a Million

By ELIZABETH JANE WALKER

Only one kid in a million gets colorectal carcinoma each year in the U.S. Nevertheless, St. Jude researchers are working to find a cure.



**K**atie Mills is one in a million. Just ask anybody who knows this vivacious 17-year-old from Massachusetts. Not only can she hold down a job while making academic honor roll, but Katie can also manage a frenetic social schedule while finding time to work in her community’s soup kitchen.

But there’s another reason Katie stands out. She’s battling colon cancer.

According to the National Cancer Institute, colorectal carcinoma is quite common in adults—ranking as the fourth most common cancer. But in children, it’s a different story. Only one American in a million under age 20 is found to have the



disease each year. One in a million. To researchers at St. Jude Children's Research Hospital, that number is simply too high.

## Step by step

For the past three decades, Janet Houghton, PhD, has waged her own war on colorectal cancer, armed with an artillery of intellect, training, dogged determination and a bit of luck.

Houghton, of the St. Jude Hematology-Oncology department, focuses her attention on finding new therapeutic approaches for colorectal carcinoma.

Colorectal cancer is a wily adversary because the disease is notoriously resistant to chemotherapy.

Nevertheless, Houghton's life's work has been to find the best way to treat this cancer. Little by little, discovery by discovery, she is moving steadily toward that goal.

For many years, Houghton has been interested in a drug called 5-fluorouracil, which has long been used to treat colorectal cancer. In the laboratory, she found that this drug was more effective if combined with another drug called leucovorin. Sure enough, by giving these drugs together, clinicians found that they could double patients' response rates.

About 10 years ago, Houghton began focusing on the role of sensors called death receptors. These proteins intercept signals from outside the cell that tell the cell to undergo apoptosis, or cell suicide. A death receptor gene called *Fas* is a major part of the mechanism that is turned on by external signals. But when *Fas* is at low concentration and doesn't work, a defective cell doesn't commit suicide; instead, it keeps on dividing and causes cancer.

## Eureka

One autumn day in 1996, Houghton asked a technician in her lab to run a certain experiment. It proved to be one of the first studies to show that signaling through the *Fas* death receptor could be extremely important in regulating apoptosis in cancer cells.

"Some things you do, and they don't pan out," Houghton observes. "But this one did. I just had a hunch. We were really lucky, actually."

After that discovery, Houghton knew she was on to something. She reasoned that if she could elevate the level of *Fas* expression in a cancer cell, then she could make it more sensitive to the anti-cancer drugs 5-fluorouracil and leucovorin. Houghton found that a third drug called interferon gamma was just the ticket for elevating *Fas* expression.



**Janet Houghton, PhD, of Hematology-Oncology is finding exciting new approaches for treating colon cancer. The fourth most common cancer in adults, colorectal carcinoma is highly resistant to chemotherapy. By using novel drug combinations and studying gene expression, Houghton and her colleagues are determined to create an effective therapy for this deadly disease.**

"I thought we were ready to try this out in patients," Houghton recalls.

## Partners for a cure

Because colorectal cancer is much more prevalent in adults than in children, Houghton knew that she would need to test the combination first in adults. "By doing that, we can obtain large numbers of patients and answer our questions quite quickly," she explains. Houghton partnered with Lee Schwartzberg, MD, and other physicians at West Clinic in Memphis, a medical group that treats adult patients with cancer. The scientists and physicians designed a clinical trial based on Houghton's data.

Schwartzberg says he is excited to work with St. Jude to find a cure for a disease that is so prevalent among adults. "Even today with our best therapies, the average lifespan for adults with metastatic colon cancer is under two years," he says. "So there's an urgent need to develop new programs."

Beginning in 2000, 25 adults with cancer of the colon and pancreas were treated with the three-drug combination. The results were promising, with many tumors stabilizing or shrinking during therapy. "We even saw responses in heavily pretreated patients," Schwartzberg says. "Typically, when adults get to the second or third line of treatment, virtually nobody responds to a new treatment."

As soon as that clinical trial was complete, the team embarked on design of a second study. A Phase II trial began a couple of months ago. This study will enroll about 70 adults with colon cancer during the next two years. The physicians will look at how well and how long the patients respond to the three-drug combination.

Houghton and her colleagues from departments across the institution will work together to analyze tissue samples before and after the first course of therapy. This team will look for genes that are expressed in response to the drug treatment. They will investigate whether the appropriate biochemical pathways are being activated or inhibited during therapy so that the drugs trigger cell death. The scientists will also study the effect of drug treatment on the expression of genes at the RNA and protein levels.

"This is the only trial of its kind that I know of," Houghton says. "I think we are on the way to having a very effective therapeutic strategy for treating colorectal cancer in both adults and children."

For adults, that's great news. And for those "one-in-a-million" kids like Katie Mills, research such as Houghton's makes all the difference. ●

# It's How You Play the Game

BY ELIZABETH JANE WALKER

The stakes were high; the medical treatment was the best available. The contest came down to one of mind and spirit.

*The 4-year-old sprints down the basketball court, dribbling a ball that seems impossibly large, moving toward a goal that is hopelessly high. As the ball sails upward, time is suspended—a mother holds her breath, a father stands transfixed. Swish.*

James White has always loved basketball; as soon as he could walk, he toddled toward a miniature goal to dunk his ball again and again. In 1998, the kindergartner was thrilled when his parents announced a family trip to Florida, where he and his brother would watch the Orlando Magic play



ball. But the Whites never made it to the game. One afternoon, the phone rang. Their house had burned. The only clothes they owned were the ones in their suitcases; their only toys were the ones in the hotel room.

“I was in shock when we drove up and saw our house,” James recalls. “Everything was black. The toys in my room were all melted. All of my stuff was ruined.”

### Game plan

Coaches often encourage players to glean life lessons through challenges encountered on the basketball court. James’ parents, Lynn and Bill White, learned that crises could arrive as silently as a wisp of smoke, but that insight could come, as well.

When the family moved into temporary housing, people in their church

provided meals and encouragement. “I remember laying my head down on the pillow at night thinking, ‘You know, I have a roof over my head and something in my stomach. And lots of friends,’” observes Bill.

After moving into the apartment, small knots arose on James’ scalp. At first his parents thought the 6-year-old had bumped his head. But more lumps appeared. Seeking answers, they visited a general practitioner, then a dermatologist. Finally, a pediatric surgeon said, “We suspect leukemia. You need to go to St. Jude.” Lynn recalls a sense of unreality. “I started feeling like, ‘This isn’t really happening to me. It’s just somebody I’m seeing on TV,” she says.

The next day—exactly three months after their house fire—the Whites arrived at St. Jude Children’s Research Hospital. Bassem Razzouk, MD, of Hematology-Oncology delivered the news: James had T-cell acute lymphoblastic leukemia (ALL) and a small mass in his chest. “Children with T-cell ALL need stronger treatment than children with the common form of ALL,” Razzouk told them, “and they have a higher chance of relapse.”

That day marked the beginning of a contest more challenging than any basketball game little James had ever played. It was also a time of introspection for his parents.

“When your child is diagnosed

with cancer, whether you verbalize the words or whether they just resonate deep in your soul, there are the words, ‘No, God, not *my* child!’” Bill says. “But I got to thinking. Just as much as I love James, God loves him even more. There are two simple truths you grow to understand: First, your child is a gift, not a possession; second, James will be healed, I just don’t know where—it may be on this earth, and it may be in heaven. But would I rather have him in my hands or in God’s hands? I’d rather him be in God’s hands.”

### Setbacks and comebacks

Soon Lynn and Bill learned another truth: “If there’s a rare side effect,” says his mom, “James will get it.”

During his treatment, James battled such ailments as chicken pox, shingles and histoplasmosis. He developed severe reactions to the most common, over-the-counter medicines. But the most serious crisis occurred July 3, 1998, when a chemotherapy drug triggered seizures and a stroke.

James’ brother was with him when the seizures began. “I had always had a feeling that he was going to be okay,” Eddie recalls. “But when he had those seizures, I was really scared that something might happen to him.”

His parents called 911. Each minute seemed interminable as they waited for the paramedics.

Awaiting the ambulance’s arrival, Bill ran out of the apartment into the brutal summer sun. Suddenly, he heard a bird singing. That simple, everyday sound gave him pause.

“I thought about how many times in the morning I wake up and hear the birds sing,” he says. “Then I began to realize that in the middle of that chaos and confusion and hurt and pain—not knowing what the next moment would bring for my child—God was simply saying, ‘I’m still here. I will never leave you nor forsake you.’ He wasn’t promising an outcome, but he would be there with us.”

**Now 13 years old, James (foreground) plays a pickup game with Joseph Amagliani and Sam Andereck, two of many friends who supported him during treatment.**



SETH DIXON



SETH DIXON



BIOMEDICAL COMMUNICATIONS

**James’ journey had a profound impact on the entire White family, says Eddie (shown at left with his brother, James, and parents, Lynn and Bill). “I think it kind of defined who we are now,” Eddie muses.**

**James’ fascination with basketball provided a diversion even when he was struggling with nausea, weight gain and fatigue. Here, he meets Memphis Grizzlies player Jason Williams.**

of James’ cerebrospinal fluid. What the scientist saw through his microscope was chilling: leukemia blasts. James’ cancer had returned.

Soon after the relapse, Razzouk and Ching-Hon Pui, MD, of Hematology-Oncology attended a national conference where they conferred with other physicians about James’ case. Razzouk called the Whites from a pay phone outside the hotel to discuss the situation.

“I told our friends and family later about what Dr. Razzouk and Dr. Pui had done,” Bill recalls. “They said, ‘You mean your doctor takes the time to call you from a pay phone? At night?’” Later, the Whites mentioned that reaction to Razzouk. He simply looked at the couple and said, “Well, you’re like family to us.”

James underwent a year and a half of rigorous treatments. “The first go-round was a breeze compared to the relapse protocol,” Lynn says. “But people all over the world were praying for him. That really helped carry us through.”

Finally, in May of 2002, James finished treatment. Since then, he has returned to the basketball court and has maintained straight A’s in school. Although the family only visits St. Jude a couple of times a year now, they have not forgotten what they learned there.

“Every day when you walk through the door of that hospital, those children teach you a valuable lesson,” Bill says. “It’s one that we all know as grownups, but we don’t always apply: that you live life one day at a time. We believe we have to think about next week and next month and next year, but the truth is that none of us knows what the next day will bring. That’s probably the neatest lesson you learn at St. Jude—just to cherish each day.”

*On a warm spring afternoon, James shoots hoops with four of his closest friends. Glistening with sweat, the young athlete bobs and twirls, feints, leaps and, hovering in midair for one miraculous moment, shoots. Shouts of jubilation; slaps on the back; a brief grin. Then the ball goes back into play.●*

The next day the Whites learned their son had no neurological deficits from his ordeal. In fact, he wanted to shoot firecrackers to celebrate July 4. A post-doctoral fellow in the Intensive Care Unit arranged for James and other children to watch the city’s fireworks display from an office on the hospital’s top floor.

“That was above and beyond—but that’s the kind of thing they do at St. Jude,” Bill says. “It’s a different world there. God uses those doctors and nurses in a mighty way. In other places, it’s not easy to get that type of care and concern.”

### Slam dunk

*The first-grader awakens on a hot May morning, nauseated and weak from the previous day’s chemotherapy. After throwing up all morning, he resolutely laces athletic shoes and convinces hesitant parents to take him to field day.*

*Arriving at school minutes before his event, he approaches the starting line. With parents and friends watching in disbelief, James handily wins the 100-yard dash.*

Throughout his treatment, James doggedly continued participating in sports. The only time he slowed was when radiation treatments sapped his energy.

“Sometimes just walking from the car to the door would make me tired,” he recalls. “But I learned that if you stay with it, sometimes it will get better. A lot of times, I felt like it couldn’t get much worse, so it had to get better.”

After two-and-a-half years at St. Jude, the big day finally arrived: James would celebrate his last chemotherapy treatment. The cake was ordered. Doctors and nurses gathered to sing the hospital’s traditional “No Mo’ Chemo” song, throw confetti and squirt Silly String.

But in an upstairs laboratory, a pathologist had completed one final check



# Perspective

## Singing the Praises of St. Jude

By Kallen Esperian

“The work St. Jude does is the most important work, really, that exists. They’re saving the lives of innocent children.”



Opera star Kallen Esperian is an ardent supporter of St. Jude.

meet employees who are thrilled to be there doing what they’re doing, and you encounter families who are thankful to be there getting help.

Around the world, there are thousands of worthy causes. But there is no higher calling than to help save the lives of children. The work St. Jude does is the most important work, really, that exists. They’re saving the lives of innocent children. And through their research, they not only save the lives of children in Memphis, Tennessee, but the lives of people in New York, Rome, Beijing and all points in between.

My husband, Tom, and I have an 11-year-old son who plays basketball and baseball and soccer. There’s nothing more fun than watching John play.

Mention St. Jude Children’s Research Hospital, and one word comes to mind: *grateful*.

Someone once said, “You can never be truly happy until you are grateful.” St. Jude reflects the truth of that statement. When you walk into the hospital, you don’t feel a depressed atmosphere, or think, “Oh, it’s so sad; these poor children.” Instead, you feel happiness. You

Looking at him, I count my blessings that he is in good health. I talk to John about St. Jude and the work that they do there, telling him about what those children go through, and encouraging him to remember how fortunate he is.

If you visit the hospital, you’ll be constantly amazed at the courage shown by those children, their parents and the doctors. It’s really staggering. I don’t

know how I would react if I were in that position. These parents are cheerful, and they’re so glad to be able to get help for their children. I enjoy visiting with them, singing for them and hopefully spreading a bit of good cheer.

It’s a joy to help St. Jude. I’ve performed benefit concerts, sung the national anthem at marathons, sung Christmas carols for the families and recorded public service announcements for the hospital. In July of 2000, I even had the privilege of singing at the funeral of Rose Marie Thomas, the wife of hospital founder Danny Thomas.

Contemplating the multitude of blessings in my life, I’m grateful that there’s a place where children and their families can come for healing and hope. You can’t even describe what St. Jude means, because it’s beyond words. It’s almost trite to talk about how worthy and how special that place is. I would simply recommend that anyone wanting to know about St. Jude should visit the hospital. After that, no explanations are necessary.

*World-renowned opera star Kallen Esperian has often shared the stage with such legends as Luciano Pavarotti and Placido Domingo. But the breadth of her talent has also propelled her into other areas of the music industry. For instance, last month, she released Lover, Come Back, songs of lost love from the Big Band era. For more information about Esperian, visit [www.kallenesperian.com](http://www.kallenesperian.com).*



Bill Murray displayed his patience, comedic skills and golfing prowess at this year’s FedEx St. Jude Classic. “For five or six hours on the golf course, he never lost his sense of humor and was always more than willing to sign autographs and talk to the crowd and just be...Bill Murray,” says St. Jude patient and current ALSAC employee Joel Alsup, who served as the comedian’s caddy. Famous for his roles in *Saturday Night Live* and more than 35 films, Murray seemed to enjoy the part he played in the fund-raising event, entertaining the crowd and signing autographs for numerous St. Jude patients.



Non-Profit Org.  
U.S. Postage  
PAID  
Permit No. 1112  
Memphis, TN

CHANGE SERVICE REQUESTED



**St. Jude Children's  
Research Hospital**

ALSAC • Danny Thomas, Founder

**332 N. Lauderdale St.  
Memphis, Tennessee 38105-2794**

Public Information: 1-866-2STJUDE (278-5833), ext. 3306

Donations: 1-800-822-6344

Visit our Web site at [www.stjude.org](http://www.stjude.org).

***Finding cures. Saving children.***

*St. Jude Children's Research Hospital,  
American Lebanese Syrian Associated Charities  
and ALSAC are registered trademarks.*