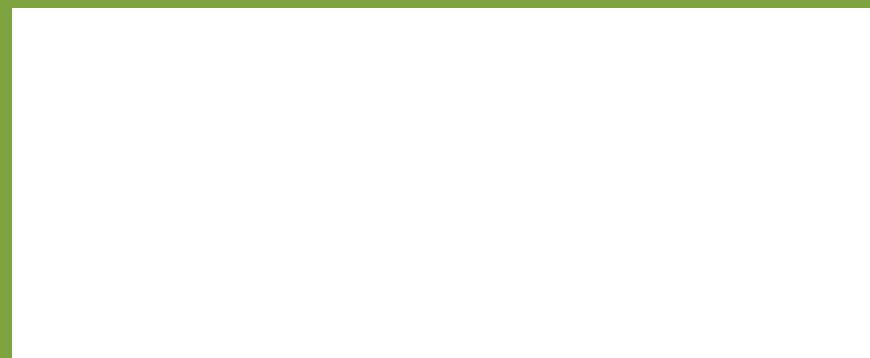


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# Promise

A publication of St. Jude Children's Research Hospital Winter 2003



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

"Show me my way in life," Danny prayed. In return, Danny promised to build St. Jude Thaddeus a shrine. That shrine became a hospital that would treat 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  
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332 N. Lauderdale  
Memphis, Tennessee 38105

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

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# Promise

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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/Promise](http://www.stjude.org/Promise). Articles and photos may be reprinted with permission. ©2003. *On the cover:* St. Jude patient Valery Young touches the fairy that she inspired in the hospital's new mural. Photo by Laura Hajar.



# Highlights

SETH DIXON



In the arms of 6'10" Memphis Grizzlies forward Drew Gooden, St. Jude patient David Cooper has a birds-eye view of the Memphis Grizzlies House groundbreaking festivities.

## New den for Grizzly cubs

Players and owners of the Memphis Grizzlies NBA team donned hardhats and wielded shovels during recent groundbreaking ceremonies for a short-term stay residence at St. Jude.

The Memphis Grizzlies House will

provide a home-like environment for patients and families who are undergoing treatment at St. Jude from one to seven days. Out-of-town families are currently housed in a nearby hotel for short-term visits.

The Grizzlies pledged \$5 million

toward construction of the \$10 million building, which is scheduled for completion in December 2003. The 70,000-square-foot structure will accommodate up to 100 families at a time. There will be no cost to families staying at the residence, which will be the only housing facility on the hospital campus.

## Sickle cell grant

St. Jude will receive a multi-million dollar, five-year grant to expand its sickle cell disease program. The hospital is one of 10 federally funded comprehensive sickle cell centers to receive a grant from the National Heart, Lung and Blood Institute of the National Institutes of Health. When funded in April, the St. Jude grant is estimated to exceed \$9 million.

The grant includes five local projects focusing on stem cell transplantation, pneumococcal infection in sickle cell patients, combination drug therapy, gene therapy and molecular biology of hemoglobin development.

A multi-center project will examine the effectiveness of the drugs hydroxyurea and magnesium to combat clinical complications of sickle cell disease.

## c-Myc and tumors

St. Jude researchers recently discovered that the *c-Myc* gene is essential for tumor development. Scientists have long recognized that *c-Myc*'s effect on cell growth can contribute to cancer development. But they have also suspected that *c-Myc* plays roles in the progression of malignancy.

A team including John Cleveland, PhD, and Troy Baudino, PhD, of Biochemistry discovered that *c-Myc* is

essential for the production and growth of blood vessels in tumors. Researchers may be able to use this information to cut off the blood supply to tumors and thwart tumor growth. The study was published in the October 2002 edition of *Genes & Development*.

## Proteins and hearing

Scientists have discovered that prestin, a cell membrane protein, is the motor protein that allows sound amplification crucial to mammalian hearing. The study, led by Jian Zuo, PhD, of Developmental Neurobiology, was published in the September 2002 edition of *Nature*.

The inner ear contains an amplifier that increases its sensitivity to sounds. The amplification depends on the outer hair cells in the cochlea changing their lengths in response to voltage changes. Zuo and his colleagues found that prestin enables these cells to change length. Mutations in the *prestin* gene may cause human deafness.

The St. Jude discovery will help scientists who study deafness and want to better understand the mechanisms of hearing and deafness.

## Tracking a killer

St. Jude researchers have been tracking a killer strain of influenza and have identified the strategy it used to slay its victims. This virus uses one of its genes to circumvent the host's immune responses.

A team of scientists led by Robert Webster, PhD, of Infectious Diseases has been studying a deadly influenza virus that emerged in 1997. Webster, Sang Heui Seo, DVM, PhD, and Erich Hoffmann, PhD, discovered that the virus' aggressive tendencies were linked to the *NS* gene. This gene encodes a protein that helps the virus avoid infection-fighting proteins produced by the body.

The discovery will help researchers who study influenza viruses and those who develop drugs to fight the flu.

The study appeared in the August 2002 edition of *Nature Medicine*.

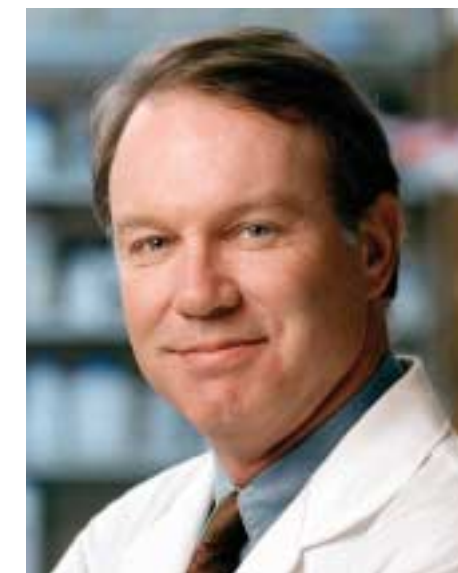
## National honors

Arthur Nienhuis, MD, and William Evans, PharmD, are among the newest members of the Institute of Medicine, a prestigious branch of the National Academy of Sciences. Nienhuis is the director of St. Jude, and Evans serves as the hospital's scientific director and deputy director.

Members are chosen for their significant contributions to health and medicine or to related fields. The institute's members devote a significant



Arthur Nienhuis



William Evans

amount of volunteer time as members of committees, which engage in a broad range of studies on health policy issues.

"It is an honor and an opportunity to provide advice and service to the government and other policy-making bodies," said Nienhuis.

## Endorse their future

Whether paying bills or buying groceries, consumers are telling a story of hope when they use these new checks designed by St. Jude patients. Produced by CheckBoxes Direct, the special checks cost \$22, with \$11 of the purchase price returning to the hospital.

To order a set of St. Jude checks, log onto [www.stjude.org/checks](http://www.stjude.org/checks) or call the CheckBoxes Direct customer service line toll-free at (866) 622-7136.







LAURA HAJAR

# The Tour des Kids

A German bicyclist climbs mountains, traverses plains and grants interviews in a fund-raising and awareness-building ride for St. Jude.

\$1,500 in donations and, more importantly, touting the St. Jude mission.

Günthör's trek began April 11 in Peoria, Illinois,

Friedrichshafen's sister city and the location of a St. Jude affiliate. He traveled through 40 states, Mexico and Canada before returning to Peoria Sept. 8.

Günthör's 2002 bike tour was his second ride for charity. In 2001, he had pedaled 5,441 miles across Europe for other charities. Following the September 11 terrorist attacks that year, he wanted to do something to help people in the United States. Because the American people's generosity had swelled the coffers of charities assisting victims of the terrorist attacks, Günthör turned his attention to another worthy cause—St. Jude. "My goal is to raise funds and awareness," Günthör said. "[I want to] speak to more newspapers, do more interviews. More interviews means the message is spread."

By the time he had peddled to Memphis in late August, Günthör

had already granted 68 interviews to newspaper reporters. "If one person reads the newspaper and maybe speaks to others ... It is impossible to imagine how far this reaches," he said. Although the money Günthör raised will help offset the costs of treating St. Jude patients, the cyclist knows that the attention he has drawn to the hospital will have the greatest impact. "In a way, I save lives," Günthör observed. "And other lives are touched in a positive way."

Günthör was greeted with a hero's welcome when he returned to Peoria in September, escorted into town by a horde of bicyclists known as the Illinois Valley Wheelmen. After accepting awards and talking about his experiences on the American highways, he returned home to Germany September 14.

"Alfred Günthör's dedication to the children of St. Jude is a marvelous display of kindness," says Dave McKee, chief operating officer for ALSAC, the hospital's fund-raising arm. "We truly appreciate his embracing our dream here at St. Jude."•

BY JOE HANNA

A German cyclist recently braved the blazing Southern sun, scaled America's steepest slopes and pushed his muscles to the max as he pedaled more than 10,000 miles in the name of St. Jude Children's Research Hospital. "In everything we do," said Alfred Günthör as he sat in the Danny Thomas/ALSAC Pavilion this past August, "we want to cause something [to happen] in a positive way."

Günthör tried to do just that by traveling across the North American continent to raise money and awareness for St. Jude.

"My heart is beating for children," says Günthör, who hails from Friedrichshafen, Germany. "They are our future." To help ensure that some children would have that future, Günthör spent six months pedaling across the country, raising

## Investments for Life

JOHN AND MILDRED JOHNSON GAVE THEIR MONEY AND THEIR HEARTS TO ST. JUDE, AN INVESTMENT THAT WILL SAVE LIVES FOR YEARS TO COME.

BY ALICIA H. MATTHEWS

The late John Johnson of Castile, New York, spent many years as a farmer and postal clerk before becoming what his friends describe as an "astute investor." He was not only an investor in financial matters, but he and his wife, Mildred, also sought to help those less fortunate in life. They invested in their local community and in various charitable causes. St. Jude Children's Research Hospital was one of those investments.

It was an investment they believed in so much that the couple bequeathed \$5 million to the hospital following John's death in 2000. Mildred had passed away in 1999.

The Johnsons made their first donation to St. Jude in 1983 after hearing about the institution's life-saving work. From that point on, they made ongoing donations to the hospital. Their commitment was such that each year during vacation, they stopped in Memphis to visit St. Jude. These visits reminded the couple why their donations were so important.

Harold Parker, executor of the Johnson estate and one of John's high school friends, describes the Johnsons as generous people who



might cause cancer and other catastrophic neurologic diseases. The Johnsons' gift will help further necessary research in this area.

"The substantial bequest from the Johnson estate provides long-term support for the research efforts in the department of Developmental Neurobiology," says department Chair Tom Curran, PhD. "We are using these resources to launch imaginative initiatives in translational brain tumor research designed to pioneer new therapeutic strategies for this devastating disease."

Because of the Johnsons' many gifts and their overwhelming generosity to the children of St. Jude, the Developmental Neurobiology wing on the second floor of the Danny Thomas Research Center has been dedicated in their memory. Parker attended the dedication ceremony and unveiled the plaque that pays tribute to his friends.

Thanks to the support of people like the Johnsons, St. Jude will continue to make strides in research and treatment of children suffering from life-threatening diseases.

To learn more about ways to give, call the Gift Planning department at (901) 578-2081, or toll-free at (800) 877-5833, ext. 2081.●

were always willing to give what they had to make life better for others.

"John and Mildred never had children," says Parker. "Because they had none of their own, they dedicated their lives to helping children in need. They also understood how important research is in helping save these children."

That's why their \$5 million estate donation to the department of Developmental Neurobiology at St. Jude is so appropriate.

Scientists in Developmental Neurobiology analyze how the brain and nervous system develop and function. The goal of this research is to understand abnormalities that





BY ELIZABETH JANE WALKER

Robert Woodward stood at the pinnacle of success in both academics and athletics. Then a brain tumor called ependymoma tested his bravery, strength and determination.

**I**n 1999, Robert Woodward became the first boy in history to sweep all Class 7 events in the Oregon state gymnastics championships. Soon after this triumph, the diminutive 9-year-old set his sights on a loftier goal: the U.S. Olympic team. He knew that he would have to log tens of thousands of hours in the gym, fine-tuning his muscles and building super-human stamina. He expected to twist, vault, stretch and somersault across the challenges and competitors in his way.

Then Robert met an obstacle more unyielding than the pommel horse and more unpredictable than the rings: a rare brain tumor called ependymoma.

### A whirlwind of wins

The terms “mediocre” and “average” have never been used to describe Robert, but the labels “genius,” “talented” and “driven” have been applied by many of his admirers. Born in Korea and raised in Maryland and Oregon, Robert was counting to 40 and reciting the alphabet by the time

he turned 2. While most of his peers were stacking blocks and playing in the sand box, Robert was already exhibiting intense intellectual curiosity, uncommon determination and outstanding athleticism. His parents were not surprised when, in the third grade, Robert scored in the top 1 percent in state-administered intelligence tests.

Recognizing that their son was physically and intellectually adroit, Ju and Woody Woodward made a commitment to encourage his interests. Robert has taken dozens of classes in areas ranging from swimming and fencing to high-powered rocketry and animation. Other moms might find shoes and toys scattered on their kitchen floors; Ju is more apt to find a 7-foot-tall rocket standing in the middle of hers. “If we can scrape the money together to let him try what he’s interested in, then we do so,” says Woody. “If he likes it, we let him decide whether he wants to continue.”

When Robert was 5, he decided to study taekwondo; two-and-a-half years later, he had earned a black belt and had won numerous gold medals in state and international competi-

DEAN ATKINS, TIMELESS IMAGES



*A nine-time Oregon state gymnastics champion, 13-year-old brain tumor survivor Robert Woodward has Olympic aspirations.*

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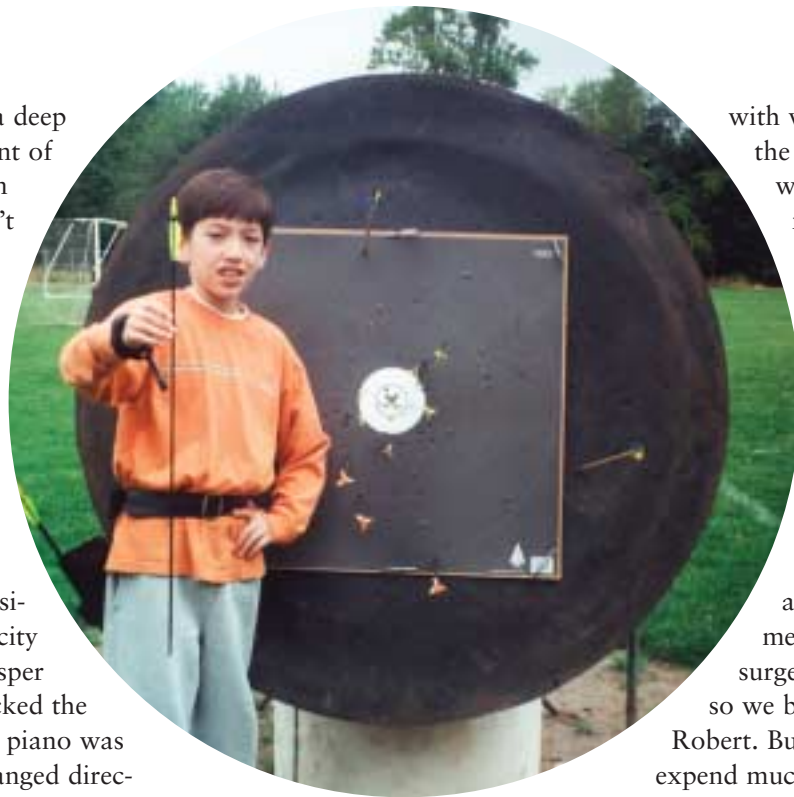
tions. With aplomb and a deep calm, he competed in front of 20,000 cheering people in an NBA arena. “You can’t believe how incredible he is about focusing,” marvels his dad. “Most kids get real nervous when they compete, but Robert gets better when he competes. He rises to the occasion.”

At age 6, Robert began studying piano, whizzing through the musical curricula at such velocity that people began to whisper “virtuoso” when he attacked the keys. But he decided that piano was not his passion, so he changed direction. He channeled his musical energies toward classical guitar, an instrument that has intrigued and inspired him ever since.

Robert took a similar attitude toward taekwondo; in spite of his phenomenal success in the martial arts, he opted to pursue gymnastics, where he could capitalize on his innate flexibility, agility and precision. Like a child layering winter coats, he constantly piled on more activities—playing soccer and chess, choreographing elaborate aerial ballets for stunt-kite competitions and wielding bows and arrows with finesse. In July of 2000, Robert entered his first archery tournament, the Oregon state championship. Once again, he prevailed—vanquishing all opponents to win his division.

### A new opponent

The highly competitive fourth-grader accrued a seemingly endless river of blue ribbons, trophies and gold medals, winning the all-around, or top honors, in every gymnastics meet. Then, early in 2000, he began to lose his edge. The differences were subtle, practically imperceptible, but they affected his scores.



“At the beginning of the season, he was winning every all-around,” says Woody, “but by the end of that season he didn’t get a medal in any of the seven events at the statewide competition.”

In late summer, Robert began to suffer occasional dizziness during gymnastics practice. In early fall, he began having episodes of nausea and vomiting. When Ju and Woody took him to the local emergency room, the doctors found nothing wrong and sent him home. The symptoms escalated, culminating in a weeklong bout

with what Robert assumed was the flu. This “flu,” however, was accompanied by monolithic headaches. “I just felt like I wanted to pull my hair out or kick a hole through the wall or something like that,” says Robert.

This time, a visit to the doctor yielded a definitive diagnosis: a tumor was growing in Robert’s brain. “First, I asked my dad, ‘Does that mean I have to have brain surgery?’ He said, ‘Yeah.’ And so we both cried a little,” recalls Robert. But the 10-year-old did not expend much effort in mourning his situation. With characteristic focus, serenity and determination, he marshaled his inner resources and approached the challenge head-on.

Robert’s ependymoma was successfully removed by surgeons at a hospital in Portland, Oregon. Afterward, the physicians recommended that Robert undergo radiation treatment, and they listed its side effects. “They were talking about things like permanent hearing loss, stunted growth and loss of mental capacity,” says Woody. “One of the side effects was that the radiation could cause cancer.” Unable to accept that their brilliant and talented son must undergo this potentially devastating treatment, the Woodwards began researching radiation options.

One name kept reappearing in their Internet searches: St. Jude Children’s Research Hospital.

### Technology and technique

On the Internet, Woody read about Thomas Merchant, DO, PhD, of the St. Jude Radiation Oncology department, and the RT-1 protocol. Through this scientific treatment plan, Merchant and his colleagues are

testing a new way of delivering radiation treatment to pediatric brain tumor patients.

As radiation destroys tumor cells, it can also damage nearby normal tissues. Physicians in Oregon were planning to treat Robert conventionally, radiating a moderately wide region of his brain. At St. Jude, clinicians would use magnetic resonance imaging (MRI), computed tomography (CT) and other measures to pinpoint the exact area—the tumor bed and a small margin around it—that must be treated. Then they would use a technique called 3-D conformal radiation therapy to focus radiation beams from several directions onto that area.

“The best way to picture 3-D conformal radiation is to imagine the spotlights or searchlights outside a movie theater at night,” explains Larry Kun, MD, chair of Radiation Oncology. “Where the beams of light overlap or intersect, it’s brighter. That

bright beam where they intersect is what you’re doing with 3-D conformal. You’re entering multiple trajectories, and the dose occurs within the boundaries where they overlap. That’s what makes it 3-dimensionally conform to the tumor.”

By limiting the radiation dose applied to the normal tissues, St. Jude clinicians can avoid many harmful side effects. With the RT-1 protocol, they are treating a much smaller area than has been treated in the past. “You don’t want to treat the tumor area too tightly, because you might actually miss some of the area that needs to be treated,” Merchant says. “So we’ve determined the smallest volume that can be safely treated without compromising tumor control.” The protocol includes extensive evaluation before and after therapy to identify the treatment’s impact on such areas as school performance, growth and development, hearing and neurological functioning.

Merchant says the technology used in the RT-1 protocol is widely available, but the experience levels at St. Jude are unrivaled. “The capability is there at other places, but the experience is not,” he says. “The RT-1 protocol is one of the largest single-institution brain tumor studies ever conducted. We have treated 185 children in just five years. With a rare tumor like ependymoma, even the larger centers will treat only one or two children a year. Over the course of five years, we’ve treated 80.”

Robert underwent six-and-a-half weeks of radiation treatment at St. Jude. As usual, he practiced good time management, mastering a new skill between appointments. He had always wanted to learn to juggle; now he had the time to learn.

“He’s an unbelievable juggler,” says Christy Bosley, RN, Radiation Oncology nurse. “He’s one of those children who makes up his mind he wants to do something

PHOTOS BY WOODY WOODWARD



Robert enjoys choreographing elaborate aerial ballets for stunt-kite competitions. Here, he attends an international kite festival in Long Beach, Washington.

Facing page: Six weeks after returning home from St. Jude, Robert entered a five-state gymnastics competition, winning the pommel horse event. On his next visit to St. Jude, he presented his blue ribbon to Thomas Merchant, DO, PhD, of Radiation Oncology. Robert is also an Oregon state champion in archery.



“With a rare tumor like ependymoma, even the larger centers will treat only one or two children a year. Over the course of five years, we’ve treated 80.”

and it just sort of happens.”

Robert *makes* things happen. A week after he returned home from St. Jude, he braved residual dizziness and nausea to resume practice. Five weeks later, he entered a five-state gymnastics tournament and won the pommel horse event. When he returned to Memphis for his next appointment, he presented his blue ribbon to Merchant.

That blue ribbon represents the



Like any teenager, Robert (second from right) occasionally finds time to relax and eat junk food with his buddies (from left), Kellan and Kameron Kadooka and Greg Bartle.



CINDY PEDERSON

Robert, who plays alto saxophone and the oboe, is already an accomplished classical guitarist.

success of the RT-1 protocol—not only to Robert, but to many other children with life-threatening brain tumors. “Robert’s doing fantastic,” Merchant says. “And he’s not the exception. Most of the kids on RT-1 are doing as well after the treatment as they were before.”

### Looking forward

Today, Robert has resumed his frenetic schedule, constantly setting, reaching and exceeding new goals. An accomplished classical guitarist, he has attracted the attention of such luminaries as Lily Afshar, PhD, one of the United States’ most accomplished classical guitarists. “He’s very serious about his guitar,” says Afshar, who adds that she was “very impressed” with Robert when she met him at a national guitar festival last year. In addition to the guitar, Robert also is learning to play the alto saxophone and the oboe. He was the lead programmer and team captain in a robotics tournament last year; he received the 2002 President’s Gold Medal for academic achievement; and he is currently plying his skills at woodworking and wood burning.

“What’s impressed me the

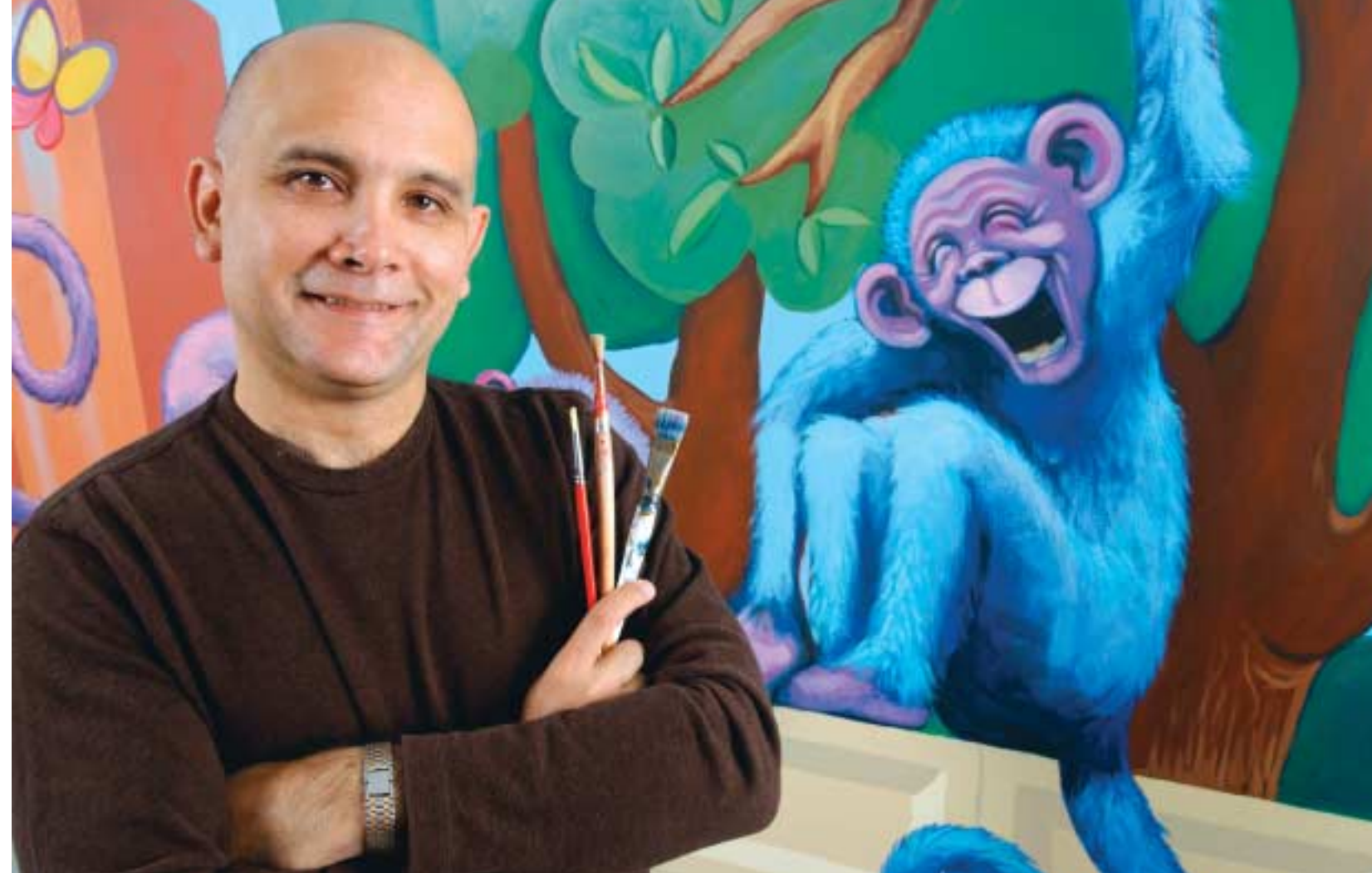
most about Robert has been his motivation to continue working really, really hard,” says Susan Chattin-Helton, EdS, Robert’s psychological examiner at St. Jude. “He never let the fact that he had a brain tumor or was going through treatment get him down. Robert’s own motivation has played a key role in his recovery.”

In spite of all his activities and accomplishments, Robert still finds time to say “thank you” to St. Jude. When his school participated in the St. Jude Math-A-Thon®, Robert created a videotape chronicling his radiation treatment. He visited each classroom, explaining why the children should participate in the fund-raising event. The school tripled its level of participation that year.

Woody becomes emotional when he contemplates his family’s experiences at St. Jude. “St. Jude is a heaven on earth,” he says, his voice cracking with unshed tears. “I don’t know where we’d be without the people there. Truly there are miracles in this world, and my son is one of them.”

What is left for Robert to accomplish, now that he has reclaimed his future? “My dream is to go to the Olympics in gymnastics,” he says. Robert is well on his way to meeting that goal, after winning two events in the 2002 Oregon State Gymnastics Championships. And after the Olympics? “I want to be a robotics engineer,” he says, “and a concert guitarist on the side.”

If Robert Woodward makes his mind up to do it, be assured: it *will* happen.●



Artist Claudio Pérez-León

## Painting the Town

BY SCOTT WILLS

PHOTOS BY LAURA HAJAR

No tour bus is necessary for this magical jaunt through the River City. In a mural that dances across the walls of the Patient Care Center, Memphis streets and landmarks resonate with the wonder of childhood and the power of miracles.

Daydreams and imagination can gently carry travelers far from the humdrum, workaday world. At St. Jude Children’s Research Hospital, a stroll along the second-floor corridors now has that same power, whisking viewers to worlds of whimsy and delight. Adorning the walls is a 4,800-square-foot mural. But to St. Jude patients,





**“When art has the capacity to shift children’s focus from symptom discomfort to their own imaginations, it is a gift from God.”**

families and caregivers, this mural represents more than a mere painting; it is a once-in-a-lifetime opportunity to physically walk through a three-dimensional storybook.

Every good storybook has a beginning, a middle and an end. This particular “once upon a time” involves a man with only two things: a paintbrush and a quest to reach out and embrace the children and community of St. Jude.

“I felt incredibly excited,” says Claudio Pérez-León, recalling the day when he was approached to work on the mural project. “For many years I had heard how great St. Jude was, and it was an amazing opportunity to do something for both kids and parents.”

Located in the center of the hospital’s second level, the completed mural represents the first of three phases. When the project’s second and third phases are finished, murals will also extend across 14,000 square feet of walls in the floor’s north and south wings.

The content and quality of the

*The colors and imagery used throughout the mural highlight the importance of escapism and imagination—two activities that children hold onto and call upon in times of need. That is why the mural contains UFOs and aliens; airplanes with faces; and characters with more than an uncanny resemblance to Elvis Presley, Oprah Winfrey and the Queen of England.*



forthcoming artwork will have a more urban and suburban resonance than that of the first phase. The last of the murals is scheduled for completion in the summer of 2003.

### A rough sketch

A scholar of architecture and fine arts, Pérez-León initially met with hospital architects and construction staff to establish the mural’s objectives. The enormous undertaking is part of an even larger renovation project designed to make the hospital’s Patient Care Center more “child friendly.”

Pérez-León, president of Artimpact Inc., envisioned the mural as a stimulating series of paintings that, seamlessly integrated, would give spectators a sense of place, character and community. With its diverse culture and heritage, Memphis offered the perfect backdrop for such a project.

First, Pérez-León created scaled, color drawings that incorporated specific landmarks such as the Memphis Zoo, the Hernando DeSoto Bridge and the musical idiosyncrasies of Beale Street. Because the artist considered the Memphis skyline to be an important aspect, the landscape displays architectural references such as the compelling Morgan Keegan tower and the gleaming Pyramid arena.

During the design phase of the Memphis city streetscape, Pérez-León introduced a novel method for determining what elements should appear in the final design. A massive sketchbook in the hospital’s second floor lobby provided a venue for patients, their parents and families to jot suggestions and comments.

Pérez-León was amazed at the number and quality of contributions. “There was a strong interactive component within this project,” he says, “not only verbally through



direct communication with the kids, but also via those people who felt more comfortable writing down suggestions.”

Some of the suggestions from families were practical: “Needs a motorcycle on the bridge!” A few were purely personal preference: “Please paint over the eyes on the bird’s bellies—they’re scary!” Other comments were charmingly profound: “We all need a little sunshine.”

### Spreading sunshine

Sunshine is just what the families have received. Completed in October 2002, the mural’s first phase radiates brilliance and warmth, inviting viewers to step into a land of color and fantasy. The painted walls are a window to a child’s imagination—animals, people and landscapes depicted in exquisite detail, all voluminously awash with a wide spectrum of color.

Pérez-León assembled a team of

talented artists to help him bring his designs to life. “It has been a great opportunity to get other artists involved,” observes Pérez-León. “Without their help and imagination this project would not be half as good.” Memphis artists Jeff Unthank, Mary Norman, Jan Hankins, Melissa Dunn, Sarah Hiles, Eric Swartz, Dylan Collier and Judith Dierkes spent many hours working on the mural, stopping occasionally to chat with St. Jude patients and siblings. Some youngsters offered their artistic advice; others even helped with the painting.

When 12-year-old Joseph Dean was an inpatient last summer, he combated boredom by helping the artists. “I painted some leaves on one of the trees, I outlined some things and I drew some other stuff,” he says, proudly. He’s quick to add that the experience did not, however, inspire him to pursue a career in art. “I still want to be a professional baseball player,” he declares.

John Haghayeghi, the 14-year-old brother of St. Jude patient Hanna Haghayeghi, spent 100 hours volunteering on the project.

“I taped walls and painted roofs and skies and roads,” John says. “It was fun, but it was tiring.” By working on the project, the altruistic young man was able to acquire valuable work experience. Pérez-León wrote a letter that the career-oriented teen plans to use in his college applications. “It also gave me a chance to help out St. Jude, because my sister was there,” John explains.

### Mermaid tails, fairy wings

Mermaids do not frequent the Mississippi River, but at least one aquatic princess splashes her tail within the mural. Artists were surprised to find that some of the younger St. Jude patients often drew mermaids when creativity blossomed in the playroom. Morgan Butler



“You hear about miracles while growing up—things that happen just once. But this place is where miracles happen one day after another, after another, after another.”

and her sister, Carly, kept bringing pictures of mermaids as presents for the artists. “The girls were both adorable,” recalls Pérez-León. “Both of them were a joy to have around

and had great impact on our lives. That’s why we included a mermaid in the mural.”

Replicating the “real world” is not the goal of this work of art. The

colors and imagery used throughout the mural highlight the importance of escapism and imagination—two activities that children hold onto and call upon in times of need. That is why the mural contains UFOs and aliens; airplanes with faces; and characters with more than an uncanny resemblance to Elvis Presley, Oprah Winfrey and the Queen of England.

Angel Young, mother of St. Jude patient Valery Young, mentioned her daughter’s fixation with fairies to artists working on the mural. The painters immediately incorporated a dazzling, lilac-colored fairy into their design. When Valery (pictured on the cover of this magazine and on the opposite page) saw the completed fairy in the mural she was so thrilled that she asked politely if she could touch it. With permission granted, Valery’s dream to experience a beautiful fairy came true.



### Homage to miracles

Most people requested that the mural include playful scenes, such as children jumping rope and girls playing dress-up. But patients and families also requested the inclusion of children who have experienced hair loss through chemotherapy treatment. One of the mural’s strengths lies in its ability to present and deal with sensitive issues. How many pieces of art in the world contain paintings of children who have suffered hair loss because of chemotherapy? How many murals contain images of children and adults in wheelchairs? This mural depicts the challenging aspects of catastrophic disease in a positive light.

“The mural has created a little world that I am very happy about,” says Pérez-León. “When art has the capacity to shift children’s focus from symptom discomfort to their own imaginations, it is a gift from God.”



Melissa Dunn, Claudio Pérez-León and Sarah Hiles were part of a nine-person team that brought the walls to life on the second floor of the Patient Care Center.

A poignant part of the mural features a room full of brightly colored masks. The masks represent the emotions a child experiences while confronting a catastrophic illness: sadness, happiness, anger,

fatigue and fear. “I wanted to produce a mural that acknowledged feelings that are not necessarily happy,” explains Pérez-León. “The tone of the mural is generally happy and optimistic, but not everyone is happy. I’m not always happy. And sometimes kids and parents are not.”

Another part of the mural features an adult man with hair loss who has undergone chemotherapy. The image of a smiling adult who has

recovered is a strong message to the children of St. Jude: survival and recovery are not only obtainable, but worth fighting for.

The first phase of the mural, which took approximately six months to complete, features its own version of “Where’s Waldo?” This edition, however, might be more aptly titled “Where’s Danny?” The object of the game is to find a miniature, painted portrait of St. Jude founder Danny Thomas hidden somewhere within the mural. This whimsical exercise pays homage to a man who understood the power of dreams and imagination.

“What Danny Thomas has done is contagious,” says Pérez-León. “St. Jude is a miracle that continues to reiterate one day after another.

“You hear about miracles while growing up—things that happen just once. But this place is where miracles happen one day after another, after another, after another.”●



Artists painted a fairy when they heard that St. Jude patient Valery Young often wore fairy wings at play. When Valery saw the fairy, she asked politely if she could touch it.



# Kinder, Gentler Research

Hinds laughs when she recalls some of her conversations with children participating in Nursing Research projects. But the studies themselves are serious. For the past 18 years, Hinds and her colleagues have been seeking innovative ways to improve patients' quality of life, to relieve their symptoms and to foster hope. "These are not studies that are going to lead to cures," Hinds explains. "They're going to contribute to cures. They're going to help patients sustain themselves during treatment so that they can withstand the rigors of treatment."

## Different ways of doing science

When Hinds arrived at St. Jude in 1985, few people had heard of her field. "A nurse? Doing research?" scoffed the skeptics.

"There are different ways of doing science," Hinds responded.

Even the Institutional Review Board was wary when Hinds proposed her first project, a study about hope. But when the protocol began, the response was

overwhelming. "I had people knocking on my door and saying, 'Are you the nurse who's studying hope? I want you to interview my child,'" recalls Hinds. "Or I'd open the door to find an adolescent with an arm around another patient saying, 'You need to talk with him about hope.' Physicians were also referring kids to the study. It was huge."

That successful project was followed by dozens of other studies. As a result of information gleaned from those protocols, many positive changes occurred in patient care at hospitals around the country. For instance, St. Jude nursing researchers created new methods for administering platelets, collecting certain blood samples and measuring patient pain and fatigue.

## Too tired to smile

Research questions often emerge as a result of problems encountered by clinicians, patients or families. When the researchers asked patients to list troublesome symptoms, they expected that pain would be

BY ELIZABETH JANE WALKER

Actigraphs—they're cool; they're sleek; they give children superhuman powers....Well, that's what some kids want to believe when they wear the devices during a patient fatigue project at St. Jude Children's Research Hospital.

Resembling slim, black watches, actigraphs measure activity levels. But sometimes children imagine that they do much, much more. One boy wanted to participate in the study because the watch resembled equipment worn by the Mighty Morphin' Power Rangers. "Whenever he felt that he needed extra protection, he held it up in front of him," says Pamela Hinds, RN, PhD, director of Nursing Research.

Another patient questioned whether the actigraph did more than record movement. "When I wear this watch can you tell when I've been bad? Because if you can, then I'll take it off just before I plan to be bad," he warned.

*Liz Burghen, RN, MSN, MBA, a nursing research specialist, explains the actigraph to 10-year-old Jarvis Harper and his mom, Latisha Harper. St. Jude researchers are using actigraphs to record activity levels in a study to evaluate sleep and fatigue in children with acute lymphoblastic leukemia.*

SETH DIXON



At St. Jude, nurses are conducting research to improve patient care, eliminate suffering and foster hope.



first, followed by nausea, hair loss and loneliness. But the children overwhelmingly cited fatigue as the most debilitating problem. “I’m so tired that I can’t even smile,” they would say. “I’m so tired that even if my best friend travels hours and hours to see me, I can’t talk to her.”

Those comments prompted Hinds and her team to begin studying fatigue and sleep. “We want to do whatever we can to help patients sleep so that they can have the growth, repair and healing that sleep promotes,” explains Jami Gattuso, RN, MSN, a Nursing Research specialist who is working on the “Sleep, Fatigue and Dexamethasone” project.

A backbone of leukemia treatment, the drug dexamethasone often induces sleeplessness in children who take it. St. Jude nurse researchers are asking some children with acute lymphoblastic leukemia to wear actigraphs for 10 days—five days before and five days during administration of the drug. A computer chip in the actigraph records the children’s activity levels.

The patients and their parents also keep diaries detailing the children’s activities, moods and fatigue levels. Those diaries help researchers explain movements that appear in the actigraph data. Frequent blood tests help researchers determine how each patient metabolizes the dexamethasone. “If we find that there is an actual change in sleep patterns, then that may indicate that we need to administer the drug differently,” says Hinds.

When Blaine Conway of Missouri takes dexamethasone, he sleeps fitfully, if at all. “When he’s taking dex, it affects our whole family,” says Robin Conway. “When I take him to school, I say, ‘We’re a dex family this week. Blaine was on dex the week after school started, and he fell asleep in class. That is so unlike him. He’s very active, but he was sleep deprived from the night before.’”

When a child is running around the house at 3 a.m., the parent suffers, too. Exhausted parents might be more apt to make mistakes when they are caring for sick children. Because the parents’ quality of life affects the patients, Hinds, nurse educator Jeri Tidwell, RN, MSN, and the Nursing Research staff are planning a new study that embraces parental sleep and fatigue.

A related project is exploring whether mild exercise will affect the fatigue and sleep levels of inpatients. Researchers also record the number of times staff members enter and exit patient rooms at night. “Several years ago we did an observational study and found that the number of entries and exits to patient rooms at night was sometimes as high as 38,” says Gattuso. “We want to make the environment

even more conducive to healing.” The researchers are interested in exploring ways to create fewer interruptions while providing the same level of care.

### More quality to life

The nurse researchers are also involved in projects that study the impact of treatment on children’s lives. One such study evaluates the effectiveness of a drug called Procrit (epoetin alfa), which is used to treat fatigue associated with cancer. Many of the hospital’s protocols, or scientific treatment plans, also feature quality of life objectives created by Hinds and her staff. If the researchers determine that the quality of life plummets at a specific point in treatment, they can create intervention plans to prevent or alleviate the problems.

Robin Conway understands the importance of such research to children such as 6-year-old Blaine. “It’s so important to improve the quality of life for these kids,” she says. “This treatment has taken three years of Blaine’s life. Anything that can improve the lives of kids

When the researchers asked patients to list troublesome symptoms, they expected that pain would be first, followed by nausea, hair loss and loneliness. But the children overwhelmingly cited fatigue as the most debilitating problem.

during treatment would be a good thing.”

Glenda Kinnebrew’s son Bryan has participated in one of the Nursing Research studies. The 15-year-old from Louisiana and his mom are thankful that the researchers address quality-of-life issues. “It’s great that St. Jude tries to make things easier on us,” says Glenda. “Leukemia is such a traumatic illness, and it affects the total family and their lives. The studies may not help Bryan, but they may help other children in the long run, so we’re willing to do them.”

### Listening to parents

Because they realize that not all children survive treatment, Hinds and her staff have conducted four studies

“When I wear this watch can you tell when I’ve been bad? Because if you can, then I’ll take it off just before I plan to be bad.”

addressing end-of-life issues. “It’s critically important for parents to know that they have been good parents when their children are dying,” says Hinds. “How the parents survive that time and how they perceive themselves as parents will mark the rest of their lives. We need to do all that we can to learn their definition of being good parents and to help them achieve it.”

Nursing researchers asked parents to help them identify

the symptoms that children are most likely to display the last week of life. Thirty-three symptoms were pinpointed as a result of the study. A new protocol will expand on that topic, examining how parents deal with end-of-life symptoms and the types of information and support they receive or need during that time.

Other studies have addressed ways that health care providers can help par-

ents make end-of-life decisions. In one study, parents of patients who had died explained the kinds of decisions they made, how they reached them and who helped them make those decisions.

“Of course, we only talked with parents who had indicated an interest in participating in such a study,” says Gattuso. “When you hear a family member tell you about the last day of their child’s life, you think, ‘I’m not worthy to hear this.’ It is such a privilege to do research with these children and their families. These parents opened up and told us so many things that were extremely valuable and that will help us immeasurably.”

### Hope is here

A multidisciplinary team of St. Jude staff members are using much of the data obtained from Nursing Research studies to create ways to foster hope in patients. “Hope is what St. Jude is all about and what it was founded on,” says Gattuso, “so it’s very important that we promote hopefulness in a therapeutic way.”

The Hope Research Translation Team has reviewed the available research about hopefulness. They have talked to staff, patients and families about the topic, and have created several projects to help promote hope. St. Jude Chaplain Brent Powell created the Hope Hotline; parents can call this phone number 24 hours a day to hear a message of hope and to leave requests for prayer or further contact. Other team members are creating educational flyers and Parent Handbook inserts about hope. The team plans to build Internet pages to further encourage hope in patients and families.

Hinds sees the Hope Research Translation Project as a healthy and natural outgrowth of the work she and her colleagues have been doing for years.

“Parents have told us that they recognize that not all children can get cured, but that they still need to have hope,” explains Hinds. “The parents know that ‘hope’ is not a promise of a cure. But it’s a promise that we will go through this with them, and a promise that we won’t abandon them, even if cure becomes impossible.

“And that’s what hope is all about.”●



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*Pamela Hinds, RN, PhD, and Jami Gattuso, RN, MSN, are involved in numerous projects aimed at improving the lives of St. Jude patients. “These are not studies that are going to lead to cures,” says Hinds. “They’re going to contribute to cures. They’re going to help patients sustain themselves during treatment so that they can withstand the rigors of treatment.” Other members of Nursing Research are Liz Burghen, RN, MSN, MBA; Cheryl Cox, RN, PhD; Brenda Steen, RN; and Linda Watts-Parker.*



# Teaching Old Drugs NEW Tricks

Using anti-cancer drugs that have been around for decades, St. Jude investigators are armed with a new plan of attack on AML.

BY TANUJA COLETTA

A visit to the 2002 Chicago Marathon Web site will display Michael Hecht's name, but not his finish time. It's not that Michael wasn't prepared; an accomplished runner, he has been training for years and even arrived in Chicago two days before the race. But while others were resting for the 26.2-mile run, he and his wife, Silvia, were racing back to Memphis. During a cab ride on the way to their hotel,

they had received a cell phone call from Silvia's sister, saying that their first-born son had cancer. Three-year-old Walker Hecht had become sick while staying with his aunt for the weekend. A doctor's visit revealed that he had acute myeloid leukemia, or AML. By the time the Hechts' plane touched down in Memphis that evening, Walker had already been admitted to St. Jude Children's Research Hospital.

Walker has the "good" kind of

AML, says Silvia. Her eyebrows arch with hope, but the shrug of her shoulders clearly says, "whatever that means." For 13 days, Silvia and Michael, native Memphians, have been on a cancer crash course, learning everything from the "good" and "bad" types of AML to the names of five-syllable drugs they hope will save their son's life. Walker is the first patient enrolled in the new St. Jude AML protocol, or scientific treatment plan, which opened in

the fall of 2002. Researchers and clinicians hope that this study will help them determine the best way to administer the anti-cancer drugs that have been used to treat AML for decades.

The Hechts are optimistic. "Even though I've lived in Memphis all this time, I'm only now learning just how excellent the doctors and staff are, and I trust them," says

Silvia, glancing at Walker as he dozes off in his aunt's arms. "He's been a real trouper."

## Cells run amok

Between medical exams, Walker, sporting khakis and a plaid button-down shirt, gouges his red Crayon onto a crisp, white canvas. Inside his small body, immature cells are growing with abandon. No one

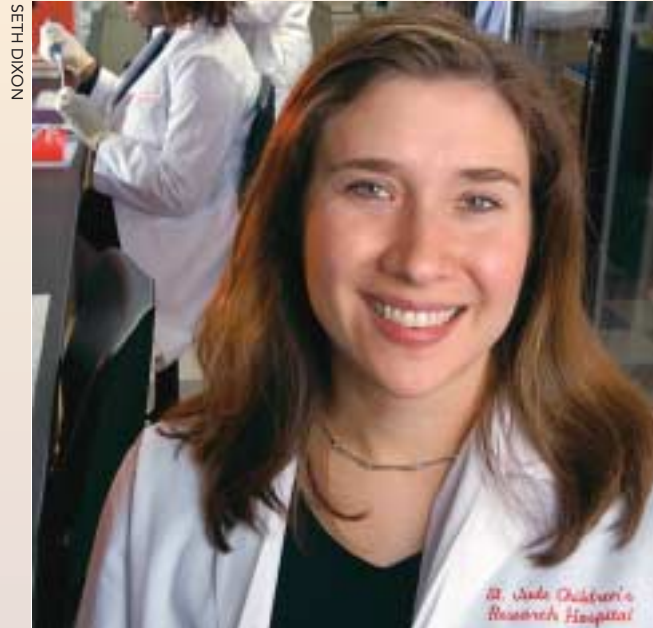
knows for sure what has triggered the genetic signals of Walker's healthy blood cells to go haywire and cause leukemia, but that is exactly what has happened.

It all started with stem cells located in Walker's bone marrow. Stem cells mature into a variety of other cells, including infection-fighting white cells; oxygen-carrying red cells; and platelets,



Three-year-old Walker Hecht is the first patient enrolled in the new St. Jude AML protocol. Researchers and clinicians hope that this study will help them determine the best way to administer the anti-cancer drugs that have been used to treat AML for decades.





NOVIG DIXON

*Kristine Crews, PharmD, of Pharmaceutical Sciences studies how drugs are absorbed, distributed, metabolized and excreted from the body. Her lab will study the effects of high-dose versus low-dose Ara-C, with half of the patients receiving one and the rest receiving the other. "Combating childhood cancer is not always about developing new drugs," she says. "A lot of times what we're looking for are better ways to use the drugs that are already out there.... It all boils down to finding the absolute best treatment for children with this disease."*

hood AML and the more common acute lymphoblastic leukemia, or ALL. He says the differences between the two leukemias are often frustrating.

"The research out there on ALL is accelerated because of the higher number of children with the disease, which also speeds up clinical trials," he says. "But also, AML is just a whole different disease. For reasons we don't know just yet, it's a lot more resistant."

Acute myeloid leukemia affects about 500 children a year in the United States, compared to 2,000 affected by ALL. Acute lymphoblastic leukemia is associated with lympho-

cytes, white blood cells that defend the body's immune system; AML targets everything else in the blood—red blood cells, platelets and bacteria-eating white blood cells known as granulocytes and monocytes. Initial remission, the absence of leukemic cells, is high for both diseases—98 percent for ALL and 90 percent for AML. But 80 percent of ALL patients go on to be cured while nearly half of AML patients relapse.

Instead of being one disease, AML is divided into seven subtypes. Some subtypes respond well to treatment (the "good" types that Silvia Hecht mentioned), and others do not. Rubnitz says that targeted therapy is the only answer for a lasting AML cure. "What would be ideal is to have individual therapies for each subtype," says Rubnitz.

"We're not there yet, but we're moving in that direction."

### Old but effective weapons

AML therapy is based on two drugs used for the past 30 years. Cytarabine, or Ara-C, and daunorubicin have been fierce weapons in attacking AML in adults. Although results have been positive with children, too, many questions about their use remain unanswered. The new St. Jude protocol may solve some of those mysteries by including numerous patients from across the country. The first AML protocol at St. Jude to include outside institutions, this study involves children from California's Stanford University Medical Center; Cook Children's Medical Center in Fort Worth, Texas; and Children's Hospital of Michigan.

"At St. Jude, we see about 20 to 25 AML patients a year," Rubnitz says. "We need to see a larger pool of patients to really answer the therapeutic and biologic questions we have on AML, because the point of this protocol is not only to improve cure rates but to learn as much as we can about the biology of the disease." While each hospital will treat its own patients using the St. Jude treatment plan, all biological samples will be studied at St. Jude.

### Asking the right questions

The laboratory where Kristine Crews, PharmD, will study patient samples from the AML protocol is just a few turns down the hallway from the rooms where Walker is treated. She says the close proximity and collaboration between research and clinical departments at St. Jude make it one of a few

institutions in the world that could take on a study like this. "We have a crucial mix of excellent patient care and closely located research labs," says Crews, who works in Pharmaceutical Sciences. "We can see what effects the drugs are having in the patients' leukemia cells in a matter of hours."

Crews' studies revolve around pharmacokinetics, the study of how drugs are absorbed, distributed, metabolized and excreted from the body. Her lab will study the effects of high-dose versus low-dose Ara-C, with half of the patients receiving one and the rest receiving the other. One St. Jude study shows that high doses of Ara-C have been effective in treating the subtype of AML that Walker has, while the same dose is less effective in other subtypes.

"Combating childhood cancer is not always about developing new drugs," she says. "A lot of times

what we're looking for are better ways to use the drugs that are already out there. Ara-C is a very old drug; yet even though it's one of the most-studied drugs for AML, we still don't know what the best dosage is."

Crews is excited about the protocol. "We're going to be able to generate a lot of crucial answers from this," she says. "We're asking all the right questions, not only what is the best way to use Ara-C in children but also what happens at the level of the genes when Ara-C is used. It all boils down to finding the absolute best treatment for children with this disease."

### Racing toward breakthroughs

One of the hottest emerging techniques in cancer therapy today is gene expression profiling. James Downing, MD, chair of the St. Jude Pathology department, has led the

hospital's efforts in the field. Gene expression profiling allows researchers to screen thousands of genes at once to reveal a person's genetic fingerprint; the process can determine a patient's risk for relapse or other complications such as second malignancies or infection by revealing how genes react to various circumstances.

For the AML study, Downing's lab, with help from the St. Jude Hartwell Center for Bioinformatics and

Biotechnology, will study patients' leukemia cells before and after treatment with Ara-C to determine the drug's effect. The results could lead to the development of more potent targeted therapies depending on what the patient's genetic disposition reveals.

"The great successes with truly targeted therapies have actually been with AML," Downing says, referring to a treatment breakthrough with the AML subtype acute promyelocytic leukemia (APL). "Fifteen years ago, patients with APL would probably die within 24 hours. Now that subtype is regarded as a curable disease." As part of a national consortium created by the National Cancer Institute, Downing is also leading parallel research that studies AML. "The hope is that we will be able to better define the various subtypes and take more and more of them into the curable range," he says. "As we develop new drugs and find better ways of administering the old ones, I would guess that 10 to 15 years from now, we'll have other AML subtypes pushing the 80 to 90 percent cure rate."

That breakthrough couldn't come soon enough for the Hechts. Michael and Silvia see a bright future for Walker, his brother, Kells, and the baby that is on the way. "I once thought that St. Jude meant gloom and doom, but I know now that it is a place of hope and survival," says Silvia.

On December 7, 2002, Michael was finally able to run a marathon. But this race was special. As he sprinted by the hospital campus in the St. Jude Memphis Marathon, Michael knew that he was helping raise money so that thousands of other children like Walker could have bright futures, too.●



SETH DIXON

*Jeffrey Rubnitz, MD, PhD, says that targeted therapy is the only answer for a lasting AML cure. "What would be ideal is to have individual therapies for each subtype," he says. "We're not there yet, but we're moving in that direction."*



# Perspective

## Going for the Gold



EVANNE NEWMAN

Tara Lipinski autographs a T-shirt for St. Jude patient Kasandra Hinton.

I first learned about St. Jude Children's Research Hospital several years ago when my mom told me the story about Danny Thomas and how he founded the hospital. She told me how the hospital helped sick children from all over the world, no matter what their financial position or walk of life. I was amazed at how the hospital flourished and that it was all brought about by one person trying to make a difference. I was truly inspired. At the time, I wasn't sure how, but I knew that I, too, could make a difference if I tried.

As an amateur skater, I visited children in hospitals as I traveled the country and world. Visiting sick children put my life and athletic competition in perspective. I got great satisfaction from getting a sick child to smile or laugh. I knew many of them did not have a lot to smile about. The more I visited these special children, the more I wanted to do it again.

By Tara Lipinski

*"Everyone can make a difference," says Olympic gold medalist Tara Lipinski, "and St. Jude is a great place to make it happen."*

Once you spend time with them, your outlook on life will change forever. Their strength and will to live is amazing. Their smiles capture the essence of life.

I once became close with a young boy who was suffering with cancer. After he passed, his grandmother wrote to me and said that I brightened his day and helped him through some tough times. Knowing that I had made a difference in his life made a difference in mine.

My first visit to St. Jude was in 1999 when my tour made its annual trip to Memphis. Every year, Stars On Ice hosts a barbecue event for the children at Target House. It was then that I fully understood the importance of St. Jude's cause. It wasn't just providing a cheerful and bright atmosphere for children undergoing medical treatment; it was the dedication of the loving staff to improve the lives of all children stricken by disease. It's a caring environment that you have to see to believe.

That day I visited with dozens of sick children, and I tried to connect with each one in some way. If I could get each one to smile or laugh, I knew I was making a difference. It's

hard to imagine what many of these kids are going through. I often wonder if I would be as brave if it were happening to me.

It was really hard to leave that day. On the way out of the hospital, I stopped in the chapel and said a little prayer. I know God has a warm place in his heart for sick children and maybe that little prayer helped one sick child. I knew as I left St. Jude that day that I would be back.

Everyone can make a difference, and St. Jude is a great place to make it happen. Learn about St. Jude. Find out what you can do to help, and do it. Whether you donate your time, make a contribution or even say a little prayer, you are doing it for a great cause. Make a difference; join me in helping St. Jude.●

*In 1998, Tara Lipinski became the youngest person ever to win a gold medal in Olympic women's figure skating. She followed that accomplishment with a successful foray into professional figure skating, winning the Ladies World Professional Championship Gold. A talented actress, she is also a perennial favorite in Target's Stars On Ice.*



JERE PAROBEK

### What a housewarming!

Olympic gold medalist Scott Hamilton reads *It's Okay to be Different*, a book by St. Jude supporter Todd Parr, to children at a celebration opening an addition to Target House. The 78,760-square-foot expansion adds 46 more apartments to Target House, a free home-away-from-home for families of children receiving treatment at St. Jude. Participating in the November grand opening event were St. Jude National Outreach Director Marlo Thomas, Grammy-award winner Amy Grant, Target Chip Ganassi Racing Team, and hundreds of patients, families and St. Jude supporters.

The new addition replicates the original Target House, where families live in the comfort of their own furnished two-bedroom apartments. The expansion includes a family activity area equipped with computers and aquariums; the Scott Hamilton Fitness Center; the Tiger Woods Performance Pavilion; the Scott Hamilton Arts and Crafts Room; and a professional day spa and meditation room.