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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

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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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*On the cover:* Cancer survivor Emily Hoskins. Photo by Brad Armstrong Photography.



# Highlights

## On the TRAIL to a cure

The protein CK2 plays a deadly role in colon cancer by blocking the ability of cancer cells to self-destruct after the cells are signaled to do so by another protein, called TRAIL. The finding was published in the January 2005 online edition of *Oncogene* by Janet Houghton, PhD, of St. Jude Hematology-Oncology.

The discovery suggests that treating tumors with TRAIL while blocking CK2 might enhance anti-cancer treatment for not only colon cancer, but for other solid tumors, as well.

## Dual function of Mcl-1

Mcl-1 blocks cell-suicide, thus ensuring that hematopoietic (blood-cell-forming) stem cells thrive and multiply—an important process during prenatal development of the blood system, according to Joseph Opferman, PhD, of St. Jude Biochemistry. This finding appeared in the February 2005 issue of *Science*.

Blocking cell suicide also permits the body to replenish the supply of red and white blood cells during life and following death of these cells due to chemotherapy and radiation therapy for cancer. But blocking cell suicide can also allow leukemic cells to thrive despite cancer therapy. Therefore, Opferman is continuing to study the activity of Mcl-1 and its role in leukemia.

## Life after treatment

New guidelines for long-term follow-up care of survivors of childhood cancers hold the promise of reducing illness and death among adult survivors of childhood cancers. The guidelines were published by a national team of experts co-led by Melissa Hudson, MD, of St. Jude Hematology-Oncology and director of the St. Jude After Completion

of Therapy clinic. Hudson is senior author of a report on the guidelines that appeared in the December 2004 issue of *Journal of Clinical Oncology*.

An estimated one in 570 young adults age 20 to 34 is a childhood cancer survivor. The guidelines are available at [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org).

## Shaping vaccine development

Scientists at St. Jude have discovered that the shape of a protein on the surface of pneumonia bacteria helps these germs invade the human bloodstream. This finding gives researchers a target on the bacteria that can be used to design a vaccine to protect children against many varieties of this pneumonia-causing bacterium, according to Richard Kriwacki, PhD, of St. Jude Structural Biology.

Kriwacki is senior author of a report published in the December 2004 online journal *EMBO*. Elaine Tuomanen, MD, chair of Infectious Diseases and director of the Children's Infection Defense Center at St. Jude, co-authored the paper.

## Circles predict success

Measuring the quantity of a certain type of a circular form of DNA found in immune cells in the bloodstream could help physicians predict whether a bone marrow stem cell transplant will be successful.

Finding large quantities of this DNA, called sjTREC, suggests that the thymus gland can successfully process transplanted stem cells into specific immune cells called T lymphocytes.

T cells arising from donated stem cells not only fight infections; some of these cells launch attacks on the patient's cancer cells—the so-called “graft-versus-tumor” response. Rupert Handgretinger, MD, PhD, director of St. Jude Stem

Cell Transplantation and co-director of the Transplantation and Gene Therapy Program, is the senior author of a report on this work appearing in the February 2005 issue of *Blood*.

## All in the family

Knowing your family's health history is an important step in understanding your own health and that of your children. St. Jude is encouraging individuals to become familiar with their family health histories and learn the important role that genes and heredity play in predicting future health. U.S. Surgeon General Richard Carmona, MD, has endorsed the hospital's participation in the Family Health History initiative he launched last year.

Information about the Family Health History initiative has been added to the “Patients and Parents” section of the St. Jude Web site at [www.stjude.org](http://www.stjude.org).

## Cure4Kids milestone

In February 2005, Cote d'Ivoire became the 100th country to join the St. Jude *Cure4Kids.org* program. Established as a part of the St. Jude International Outreach Program, *Cure4Kids* is a Web site that brings the latest medical knowledge on the treatment of catastrophic diseases of children to health care providers in countries with limited resources. The site offers a digital library, on-demand seminars with slides and audio in several languages and other resources. Since February, the site has continued to grow, with about 120 participating countries at press time.

**For more details about these items, or additional news about St. Jude, visit [www.stjude.org/media](http://www.stjude.org/media).**

# The Rest of the Story



Gene and Virginia Pugh

**“One senses that Lisa accepted the inevitability of her death long before she would admit it; that she was compelled by her love and compassion to speak to us and to open her heart, to take us inside.”** —Joseph Simone, MD, former St. Jude director

The story of Lisa Pugh is one of courage and hope. It all began in the early 1970s when the 13-year-old learned that she had acute myeloid leukemia.

“The doctor recommended that we take Lisa to St. Jude Children's Research Hospital as soon as possible,” her mother recalls. “From the very beginning, we were surrounded by love and respect. I can't describe how much that relieved some of our fears.”

For four years, Lisa struggled with her illness, keeping a diary that eloquently recorded her thoughts and feelings. These and her mother's comments were later incorporated into a book titled *Lisa's Story*.

Lisa eventually fell into a relapse, with little hope of recovery. She was given one more option—a bone marrow transplant. Because St. Jude was not yet equipped to perform this procedure, Lisa was sent to Johns Hopkins in

Baltimore, where she became one of the first bone marrow transplant recipients. Unfortunately, Lisa experienced complications and died July 21, 1975.

Gene and Virginia Pugh occasionally visit St. Jude, where they marvel at the changes in the hospital and its research facilities. “On our return visits, we still feel like there is love all around, and it can literally be felt when we walk in the doors,” says Virginia. “We have shed a lot of tears there, but we have also experienced a lot of hugs and happiness.”

Lisa's family wanted to help other patients and their families. “We are not wealthy people, but we wanted to do as much as possible for St. Jude. We can never in any way repay what the hospital has done for us and what it means to us,” Virginia says.

The family found several ways to help. Virginia named St. Jude as the beneficiary of her life insurance policy. “We pay the annual premiums, and the

BY BETH MCGOWAN

dividends accumulate, so it has increased almost three times since we bought it,” she says. “It is an excellent way to give more than we could otherwise.” They and other family members have also named St. Jude in their wills. Through these avenues, plus regular contributions, the family set up an endowment fund in Lisa's memory.

Gene and Virginia continue to be involved in hospital fund-raising projects. Through public speaking engagements, they also share the story of Lisa and the impact St. Jude made on their lives.

“Each of us is different because of Lisa's life and death,” writes Virginia in *Lisa's Story*. “Lisa taught us to accept life as it comes, with adversity and happiness, and to live each day to the fullest. Life is fragile; each day is precious; Lisa left a little of herself in the heart of each of us.”

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

## Faith

By Lisa Pugh

If the wind is blowing in your face,  
Turn around so it's at your back.

If it's raining on your side of the street,  
Cross over to the other side.

If the load becomes too heavy,  
Find someone to help you carry it.

If night comes early,  
Go to bed, and get up with the sun.

If the sun goes into a cloud,  
Wait. It has to come out the other end.

If you can't keep running,  
Think, “Only one more step.”

If all else fails, keep your chin up  
And smile on.

Brighter skies are behind dark clouds.



BY ELIZABETH JANE WALKER

IMAGE BY GOPAL MURTI, PHD

## Like substitute teachers who nab errant chair-swappers, St. Jude scientists are becoming savvy to the antics of chromosomes.

Children do it. Young practical jokers swap desks—and identities—while their substitute teacher studies a seating chart.

Chromosomes do it, too. Parts of these molecular pranksters can break off and swap places. But the outcome may be much more serious than classroom mischief. When chromosomes relocate and fuse, the results can be cataclysmic.

In a quiet corner of the Danny Thomas Research Center, Gerard Grosveld, PhD, investigates what happens when pieces of chromosomes wander from their assigned places. For years, his research has been affecting the health of people worldwide. For instance, before coming to St. Jude he led an international team of researchers that discovered how the famed “Philadelphia chromosome” is created by the fusion of the *c-ABL* gene to part of a gene called *BCR*. This new fusion gene produces a protein that is a critical player in the formation of acute myeloid leukemia.

The Philadelphia chromosome breakthrough eventually led to development of the anti-cancer drug Gleevec™.

Today, Grosveld chairs the Genetics and Tumor Cell Biology department at St. Jude Children’s Research Hospital, where he continues to delve into the secrets of gene fusion and its role in pediatric cancers, particularly leukemias and a muscle tumor called alveolar rhabdomyosarcoma.

Alveolar rhabdomyosarcoma is a malignant tumor that usually affects muscles in the trunk and limbs. Mutations in a gene called *FKHR* (pronounced “forkhead”) contribute to this disease. If a piece of the chromosomes containing the *PAX3* or *PAX7* genes breaks off and attaches to *FKHR*, a

*PAX-FKHR* fusion gene is formed that gives rise to cancer.

Scientists knew that the *FKHR* protein causes mature cells to commit suicide, but in 2003 Grosveld and his colleagues discovered another role for this molecule: It helps primitive cells called myoblasts to fuse and develop into muscles. By better understanding *FKHR*’s normal role, researchers have gained insight into how mutated forms of *FKHR* cause cancer. But Grosveld also found that expression of the *PAX3-FKHR* fusion gene is not enough to cause cancer; for that to happen, mutations must also exist in two tumor suppressor pathways. And he learned that the overexpression of certain genes that normally cause cells to proliferate also helps make cancer cells expressing *PAX3-FKHR* more aggressive.

Grosveld says the discoveries may offer hope to children with the disease.

“We have identified a way that would cure alveolar rhabdomyosarcoma,” he says. *FKHR* holds the key to wiping out these tumors. Now scientists must figure out how to do just that. The answer may lie in gene therapy or in a procedure that interferes with the breakdown of the protein expressed by *FKHR*. Grosveld favors the latter method. “We’ve still got a long way to go,” he admits. “But if we make a small molecule that interferes with the breakdown of this particular protein, I’m pretty sure that it will work.”

Members of Grosveld’s department are helping scientists across the institution understand the abnormalities that underlie the diseases treated at St. Jude. The Genetics staff is conducting research on topics ranging from the genetic alterations in cancer and lysosomal storage disorders to the genetic

changes that affect our ability to repair mutagenic insults. Researchers in his department also study the genes that are important for the formation of the eyes, the lymphatic system, the liver and the pancreas in mammals.

“The work done in that department is having an incredible impact on our understanding of the mechanisms that go wrong and lead to the diseases we see,” says James Downing, MD, St. Jude scientific director. “This research provides us with a much more detailed understanding so that we can then devise more rational approaches to diagnose, treat or ultimately prevent these diseases.”

Several years ago, Grosveld discovered a new gene that’s involved in acute lymphoblastic leukemia (ALL). Called *TEL2*, this gene regulates the action of a cell protein called mTOR. That molecule can activate a biochemical pathway that leads to cell proliferation. Grosveld and

Peter Houghton, PhD, chair of St. Jude Molecular Pharmacology, are trying to understand how *TEL2* regulates mTOR.

Grosveld has also been involved in research on *TEL* gene rearrangements. He and a team of other scientists discovered that children with ALL who have a specific *TEL* mutation have a favorable prognosis. That means those children do not need aggressive treatment and thus can avoid the side effects that often accompany cancer treatment.

When it comes to acute myeloid leukemia, Grosveld focuses on two chromosomal translocations—the fusion of the *CAN* and *DEK* genes and the fusion of the *MNI* and *TEL* genes. He and his colleagues recently discovered that overexpression of the *MNI* gene is important in certain forms of acute myeloid leukemia called CBF leukemias. “We’re trying to find out why the cells are overexpressing MN1,” Grosveld explains. “If you find

out why they’re doing that, you can interfere with the process, cut out the overexpression of MN1 and the tumors won’t grow any more.”

Downing says Grosveld’s work is having a profound impact on scientific knowledge. “His work on alveolar rhabdomyosarcoma is providing key insights into the genetic alterations that underlie the formation of these tumors; similarly, his work on acute myeloid leukemia is providing critical insights into the combinations of genetic lesions that are involved in establishing leukemia,” Downing observes.

Those genetic pranksters had better watch out. Like substitute teachers who whip around and nab errant chair-swappers, St. Jude scientists are becoming savvy to the antics of certain chromosomes. And they’re using that knowledge to send catastrophic diseases to the back of the class. ●

SETH DIXON



Gerard Grosveld, PhD, investigates what happens when pieces of chromosomes move around.





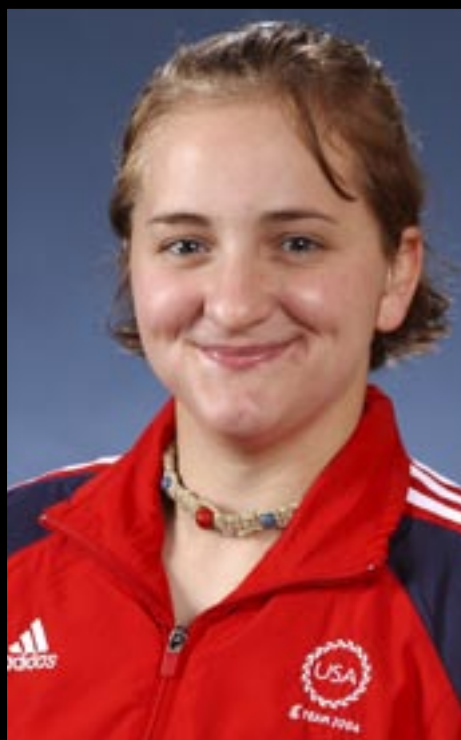
BRAD ARMSTRONG PHOTOGRAPHY

Emily Hoskins' spine was severed at birth by neuroblastoma tumors. But that setback has not impeded her ability to participate—and excel—in sporting events. She and her teammates on the U.S. Paralympic Women's Wheelchair Basketball Team (pictured below; Emily is on the second row, far left) took home the gold in the 2004 games in Athens, Greece.

LINDA HOSKINS



LINDA HOSKINS



PHOTOS COURTESY OF U.S. PARALYMPICS



# going for gold

BY VICTORIA TILNEY McDONOUGH

Whether she's accepting a gold medal in Athens, Greece, or navigating the crowded sidewalks of her university campus, St. Jude patient Emily Hoskins embodies the Olympic spirit.

If a heart can literally swell, then Linda Hoskins' heart did just that at the 2004 Paralympics in Athens, Greece. Before Emily Hoskins and her teammates had even emerged onto the basketball court in their U.S. team uniforms, the proud mother was already crying. Almost 22 years before this moment, Emily had been born paralyzed, her spine severed by a series of tumors.

pathetic nervous system. The tumors had severed her spine and damaged the nerves in her legs, causing paralysis from the waist down.

At 3 days old, Emily traveled with her father from Illinois to St. Jude Children's Research Hospital. She was the first newborn ever accepted at St. Jude.

"They had to keep her in the ICU because the hospital wasn't set up for infants," says Linda. When she arrived at St. Jude after recovering from her Caesarian section, Linda was met with cries of, "You're the baby's mother!"

"They all knew Emily," Linda recalls. "We were taken care of from the very start."

Soon Emily was known for more than just being the hospital's youngest patient. If a newborn can exude confidence and optimism, Emily did. Even when she was sick from chemotherapy, she smiled and gurgled, shamelessly flirting with her parents, the doctors and the nurses.

"I would never wish cancer on a newborn—or her parents—but I think it was easier on us because Emily couldn't talk or remember what she

had to go through," says Linda. "Also, our St. Jude doctors always talked about the future. 'This is the plan,' they'd say. 'When Emily is 1 ... When Emily goes to school ... When Emily has kids ...' That made all the difference as we looked down at our sick little girl." Ironically, Emily was fortunate that her cancer was caught at birth since infants with neuroblastoma have a much higher chance of cure than older children.

Linda and Greg knew that Emily would have challenges because of her paralysis, but they soon realized they were blessed to have their daughter alive and recovering. Emily endured chemotherapy, surgery, several serious infections and a blood transfusion.

She was pronounced cancer free at age 7. However, since Emily was St. Jude's "first baby," she returned yearly to St. Jude until she was 18 "so they could study me," Emily explains. Linda says that giving back to St. Jude this way in hopes of helping others was worth any sacrifice the family had to make.

## Embracing challenges

In fifth grade, Emily transitioned from braces and a walker to a wheelchair. "She wanted to be able to go faster," says



LINDA HOSKINS





Arriving at St. Jude in 1983, Emily Hoskins was the first newborn ever accepted into the hospital. Here, the toddler strolls along with the assistance of braces and a walker.

her mother. Because of the location of the break in her spine, Emily does not have the use of her back or abdominal muscles. But this, like every other challenge in Emily's life, has not interfered with her goals.

"If you tell Emily she can't do something due to physical ability, she will find a way to do it," says Linda. "Tell her something will be too hard, and—presto—you have given her a personal challenge, and she *will* prove you wrong."

"I don't see myself as different so I don't think anybody else should treat me that way," says Emily. "If they do, I tend to let it roll off my back. And anyway, I am no different. I'm just Emily."

## True love

Although Emily's life had been anything but dull, her world really opened up at 14 when she discovered wheelchair basketball. It was love at first try. She started playing on a regional team a few hours' drive from home. Then she studied diligently in community college to gain admission to the University of Illinois at Urbana-Champaign, home of the nation's

top wheelchair basketball program. "I remember thinking that I could've been playing all those years before," says Emily. "As far as sports go, basketball is my true love."

Emily and her teammates couldn't be closer.

"We share everything and have so much in common," explains Emily, now a senior. "When you meet someone in a chair, the details of how they got there are always your first questions. And man, you hear some crazy stories! Two friends got hit by trains. Another was run over by a lawnmower when she was 3. Another fell mountain climbing and broke her back. So I say, 'Oh, my story is boring: Survived cancer; nothing too exciting there.'"

Although she may not admit it, Emily knows that surviving cancer and becoming an independent, driven young woman is nothing short of exciting. Especially when it comes to basketball.

## Bound for Athens

"The first thing that strikes me about Emily is her absolute pure and full love of life," says Mike Frogley, University of Illinois Women's Wheelchair Basketball coach. "Her energy and vitality seem boundless; she lights fires under those around her. As a teammate, she is completely unselfish. She does whatever the team needs. The fact that she is willing and eager to play lots of different positions on the team both offensively and defensively is a testament to the kind of smart and generous player she is."

Emily was determined from the first. "She didn't start basketball being a naturally good athlete," her mom recalls. "She had to work very hard for a long time to get good. It took her months before she could make a basket."

When Emily was told that she would be part of the 12-person team traveling to Athens to compete in the 2004 Paralympics, she could hardly contain herself. She says she didn't even care if she got to play; it was all about the team doing its best.

A wheelchair basketball team must always have 14 "points" on the floor, a classification system calculated by the levels of disability. For instance, Emily is a 1.0, the lowest class, since she has no use of her back or abdominal muscles. A 4.5 would be a player who may be able to walk but has very weak knees so is still eligible to play.

"Emily has an awesome personality," says Patty Cisneros, Emily's teammate in Athens and former college roommate. "She is never in a bad mood, and I mean *never*. She just spreads good energy around. She is like this on and off the court."

Patty lost the use of her legs in a car accident at age 19. "I have learned a lot from Emily about being disabled," Patty says. "You can choose to be closed and insecure, or out there. Emily is definitely out there."

The friends enjoy going to concerts together. "Emily is incredibly comfortable with who she is. Her aura shouts, 'There is nothing wrong with me!' I never would have dreamed of dancing in my chair at a concert if it hadn't been for Emily."

## Bringing home the gold

When the U.S. Women's Wheelchair Basketball Team mounted the highest platform at the Paralympics award ceremony, everyone cried but Emily. Emily's parents and her three grandparents cheered from the stands. Twenty-one years had passed since Emily was born in distress: a lifetime; a moment.

Thinking back to that day in Athens, Emily's voice rises with excitement. "Oh, man! They come through and shake your hand and kiss you on both cheeks. They give you flowers and put one of those olive wreaths on your head, then put the gold medal around your neck. Then they raise the three flags of the countries who won gold, silver and bronze. They played our national anthem, since we won the gold," she says.

"Everyone else was crying, but I couldn't stop smiling. My teeth hurt by the end." ●



# Ripple Effect

A St. Jude educational effort may alter the course of El Salvador's HIV/AIDS epidemic.

BY TANUJA COLETTA

More than 200 extinct volcanoes remind the people of El Salvador of the danger that once rumbled across their land. Now, El Salvadorans are facing a far more deadly and widespread crisis: a growing HIV/AIDS epidemic.

Physicians from St. Jude Children's Research Hospital are helping stem the outbreak by joining with longtime partners at El Salvador's Hospital de Niños Benjamín Bloom, a local nursing society and the Ministry of Health. Last spring, St. Jude initiated a five-month training course for 100 nurses who work with HIV/AIDS-infected children. The course was the first of its kind in El Salvador, and nurses have gone on to share their knowledge with thousands of health care providers nationwide.

"The impact has been amazing," says Miguela Caniza, MD, director of the St. Jude International Outreach Infectious Diseases Program. She spearheaded the project after seeing that nurses in El Salvador were caring for a growing number of infected children, yet had little formal training on HIV/AIDS prevention or treatment.

After sub-Saharan Africa, the world's most HIV-prevalent region is the Caribbean and Central America. "St. Jude can address this because we are experts in treating pediatric HIV," Caniza says. "By exporting this expertise, we can make a difference."

## New outlook

The HIV/AIDS course focused on controlling the spread of bacteria and other infection-causing germs.

"It's still too early to measure the full impact of the training, but it will most definitely change the course of the epidemic in El Salvador," says Luis Castaneda, MD, director of El Salvador's new pediatric HIV/AIDS center. "It is visionary of St. Jude to take an interest on as big an endeavor as HIV prevention at a national level."

The nurses have already begun projects to eliminate the stigma associated with HIV/AIDS, provide teen counseling and educate the public about HIV/AIDS. "The nurses left with a new

Miguela Caniza, MD, of St. Jude International Outreach, pauses with El Salvador President Antonio Saca.

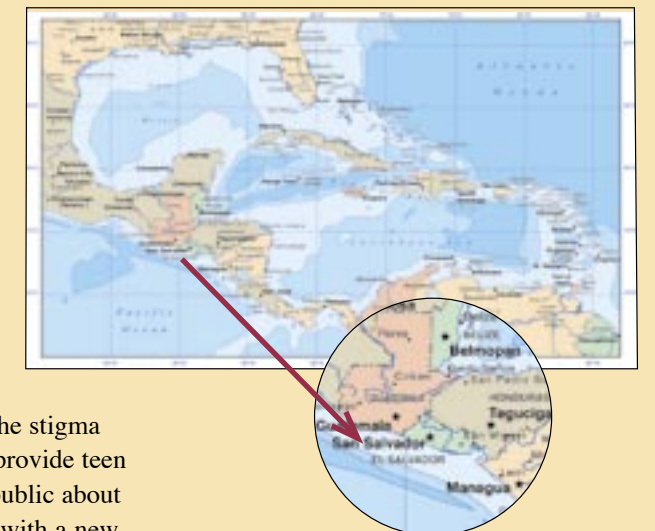
outlook on HIV," says Gabriela Maron, MD, a physician at Hospital Benjamín Bloom. "There is lots of machismo and cultural and religious barriers in our society, and our nurses left feeling that they can tear down the prejudices and be part of the solution."

## Big dreams

In 2002 when Rodrigo Siman, MD, an El Salvadoran health official, told Caniza he wanted to establish a center for treating pediatric HIV/AIDS patients, she told him to go for it.

"Why not? I think we must always dream big," Caniza says. In December 2004, Caniza attended the opening of the Centro de Exelencia para Niños con Inmumodeficiencia. El Salvador's President Antonio Saca presented Caniza with an award of appreciation for St. Jude's support in training the center's staff. Caniza is already transforming this momentum into new projects. She is creating a similar HIV/AIDS training project for Honduras and has designed an intensive infection control course for nurses from 10 Latin American countries.

"The success has blown me away," she says. "It goes to show that if you really know where to put your money and you do your best, you can make a difference." ●





BY LIN BALLEW

# TAKING ACTIVE STEPS

## Teens with HIV/AIDS travel far in St. Jude Healthy Living program.

Valerie\* wants to lose 30 pounds by prom this spring. She believes she can do it, despite the pressures she faces—juggling school and part-time jobs while raising a 12-month-old son. But Valerie also faces another obstacle: She is HIV positive.

At St. Jude Children's Research Hospital, Valerie is receiving treatment for her disease, cared for by a multidisciplinary team that understands her concern about excessive weight gain.

As a runner and an aerobics proponent, St. Jude nurse practitioner Sally DiScenza knows that physical fitness and proper nutrition can help anyone lose weight—including her patients in

the HIV Program. For years DiScenza has been telling patients about the importance of diet and exercise. But she wasn't seeing teenagers with HIV put those concepts into action.

Clinical nutritionist Karen Smith says she relates to Valerie's desire for a svelte figure. "I've struggled with my weight all my life," Smith confesses. She has also worked with HIV-positive patients since the disease was first identified in the 1980s.

"Everyone has this idea that people with HIV or AIDS are just wasting away," she says.

That was the case in the beginning. But with advances in treatments and improved medicines, more and more patients like Valerie have joined America's struggle with obesity.

### Learn by doing

Smith and DiScenza began talking about how to help their patients. Simply telling teens what to eat wouldn't work. The patients also needed physical activity.

Soon other professionals in the hospital began offering their expertise. With the approval of Patricia Flynn, MD, of St. Jude Infectious

cate them in ways that they could easily relate to when keeping up their exercises at home and when out with friends."

### Going for the goal

Another component of the program involved University of Memphis student Will Dalton, who was working as a psychology intern in the hospital's Behavioral Medicine department. Dalton taught the teens how to make changes by setting SMART goals—ones that are Specific, Manageable, Assessable, Realistic and have Time limits. Dalton taught the teenagers how their minds and thoughts can influence behavior, or vice versa.

"If you set a goal of walking 10 minutes and only walk five minutes, you can either say, 'I knew I couldn't do it,' or be more positive with an affirming statement like, 'I didn't make 10 minutes, but I made it this far. I know I can do it again,'" he explains.

Because lectures and structure are not enough to keep teens' attention, the Healthy Living leaders incorporated group outings into the program. On one such outing, they visited a grocery store to learn about food labels. The teens expressed surprise at how small changes could make significant differences in their diets.

The group also received golf lessons from a golf pro. None of the teens had ever hit a golf ball before; the novelty and adrenaline rush from the

physical activity elicited high spirits.

### Lifestyles transformed

Valerie is able to incorporate the tools she learned to transform her lifestyle and improve the health of her entire family. She and her family bake more often instead of frying food, and they use less salt than they did before she enrolled in the program. But the most important aspect, she says, is the knowledge that she's not alone in her struggles.

"It's changed my life a whole lot," Valerie says. "I didn't have anyone to talk to, but now I have friends who are going through the same thing. The staff is so loving and caring, and they always want to spend time with the patients at every visit. They seem so real."

The goals of Healthy Living were to enable teens to take control of their exercise and nutritional needs to make them healthier overall. According to Valerie, they scored. "Eating right and exercising level my mind," she says, explaining how her new lifestyle helps her better cope with problems. And she's also making progress toward her short-term goal of fitting into that prom dress. ●

Diseases, this multidisciplinary group devised Healthy Living, an educational program that would improve the nutrition and physical activity of teens with HIV/AIDS, and in so doing, help the patients control their weight.

"It's not just lifestyle issues that cause their obesity," observes Lucille Fletcher-Pope of Clinical Nutrition. "The pharmacologic agents used in their treatment also do it."

Janet Adams and Tori Marchese of Physical Therapy helped participants use workout equipment and learn aerobics routines that they could also perform at home. But several weeks into the program, the teens indicated that they'd like to do something else, as well. Adams and Marchese instituted a walking program. "They preferred walking with staff instead of using the equipment," Adams says.

What the teens didn't realize was they were getting far more than a workout. Some of the patients lacked positive role models. Employees soon discovered that their strolls with patients offered this kind of support.

"We would walk and talk about everyday things," says Adams, who kept the focus therapeutic as well as social. "As they talked about their friends, family, school—things teens talk about—I set the aerobic pace and found the opportunity to edu-

Janet Adams of Physical Therapy (at left) strolls across a bridge near the St. Jude campus with a participant in the Healthy Living program.



# Debt of gratitude

**Some St. Jude patients “give back” by coming back—working for the place that saved their lives.**

BY CARRIE L. STREHLAU

**I**n 1970, no child at St. Jude Children’s Research Hospital had yet survived Wilms tumor. Doctors told Mark Dickey’s parents that they would do everything they could. “I was two-and-a-half years old, had my left kidney removed and was one of three kids with Wilms tumor at St. Jude,” Dickey recalls. As the hospital’s first Wilms tumor survivor, Dickey was closely followed by doctors and researchers for many years.

In college, he worked for several years at the Volunteer Service Center and helped with bike-a-thons. Later, a full-time position opened in the hospital’s Information Technology Services department. “I wrote a cover letter in which I noted that I was a former patient,” Dickey recalls. “When I received a call about scheduling an interview, the person told me she was impressed with my

résumé and then said, ‘Let me tell you a little about St. Jude.’ I listened quietly and then asked if she had seen my cover letter, which she had not. I told her I knew almost as much about St. Jude as she did because I was a former patient.”

At St. Jude, Dickey helps employees use wireless communication devices and is on a team that is implementing a new way to scan patient information into the hospital’s electronic medical records.

One of his favorite St. Jude memories is of the late Charles Pratt, MD. “Dr. Pratt never forgot me,” he says. “When I first started working at St. Jude, he remembered who I was right away—even where I had had my tumor.”

Dickey sometimes shares his experiences with donors and current St. Jude patients. “When I help with tours for visitors

*I have a good life because of St. Jude.*

and donors, I say, ‘I’m working off an old doctor bill.’ That always gets a laugh,” he chuckles.

Married with one child, Dickey says he can relate to an entirely different group at the hospital. “Now, as a parent myself, I really feel what my parents’ life must have been like when I was a patient,” he says. “You can look at the numbers and statistics, but every person—every family—is different. Choose to fight and choose to survive.”

Dickey takes his battle cry to the halls of St. Jude whenever he can. “I have a good life because of St. Jude,” he says, with a smile. “That’s why I work here.”

**T**he college experience often includes staying up late to cram for tests. In 1990, Sherri Patterson’s college experience included relocating from Florida to St. Jude for surgery and chemotherapy. “At 18 years old, I was diagnosed with ovarian cancer,” she says. “I suppose it was a better age for me to have cancer because I was old enough to know what to expect—although those needles still took some getting used to. Unfortunately, cancer does not come and go on our terms.”

Although older than most St. Jude patients, Patterson was nevertheless embraced by staff members and, like other patients, tried to par-

ticipate in hospital activities. She was often too sick to eat—even on “Happy Meal” nights. “I did watch a lot of movies. They really spoiled me,” she recalls. The treatment involved surgical removal of an ovary and included a semester’s worth of chemotherapy. Patterson’s family moved to Memphis, where she remained to finish college.

She eventually came back to St. Jude, but this time with a degree in health information management. “I decided I wanted to follow a non-traditional route and focus on the research aspect of health information,” says Patterson, who works as a clinical research monitor in the hospital’s Central Protocol and Data Monitoring Office. “I think the most rewarding part of my job is working on the bone marrow transplant studies and seeing other patients also getting another chance at life. My main focus is protecting the rights and well-being of patients and helping improve the quality of research through protocol compliance.”

Being back at St. Jude allows Patterson to cross paths with some of her caregivers. “Some nurses and doctors who took care of me still work here, and I get to see them all the time,” she says. “It is such a family atmosphere when you’re a patient, and it’s nice to see them now. My family and I are forever grateful for the prayers and the compassionate care I received at St. Jude.”

Because cancer attacked her reproductive system, Patterson was not sure whether or not she would be able to have children. But today, she has a son and family of her own. Patterson has shared her experiences with employees at ALSAC and with new nurses undergoing hospital orientation. “Being a 15-year cancer survivor,” she says, “I feel a sense of freedom and relief.”

*I feel a sense of freedom and relief.*





ANN-MARGARET HEDGES



*I see things from both sides.*

*I am forever grateful.*

**J**ackie Spencer lost five pounds in one day, and she will never forget how. “On Friday, I went to the doctor, and by Monday, I was in surgery,” she says of the day in 1980. “They removed a five-pound tumor. As a 13-year-old, my biggest concern, though, was losing my hair. It eventually didn’t matter because I realized I was in a fight for my life.”

One of Spencer’s nurses was the late Bettye Arnold, RN. At the time, patients did not have central lines for when they needed blood drawn and to receive chemotherapy. “I didn’t want anyone else to stick me but her,” Spencer says. “She was so caring and my favorite nurse.”

One of five kids, Spencer lived in Arkansas with her family—a group with a very strong faith and bond. “I remember being at home with my sisters waiting on me hand and foot because I was very sick after chemotherapy,” she recalls. “I talked to God a lot, and my faith got me through it.”

Caring nurses and a strong faith led Spencer to decide she wanted to work at the hospital. “When I was a patient, I always

told people I wanted to work at St. Jude. I wanted to give back what St. Jude had given me and help kids,” she says.

Spencer started as a nursing assistant in 1990. Now she is a health unit coordinator in the hospital’s Intensive Care Unit. “I see things from both sides and have a lot of empathy for the patients and parents because I sat where they’re sitting,” she explains.

“I love teens, and I often share my story with them,” she continues. “It gives them a sense of hope, because it is hard to go through this as a teenager. I went through a stage when I didn’t want to come back for checkups, but no one knew me better than St. Jude.”

The mother of three children, Spencer says she owes everything to St. Jude. While a patient, Spencer sometimes saw Danny Thomas walking through the hospital. Today, as she takes care of St. Jude patients, she is fully aware of the debt that they—and she—owe the entertainer.

“If he hadn’t listened to his call, think about how many kids wouldn’t be here,” she says. “I am forever grateful.”



Seven-year-old Joel Alsup and Chaplain Brent Powell.

ANN-MARGARET HEDGES



*People choose how things affect them.*

*I am not going to let cancer define who I am.*

**F**or 7-year-old Joel Alsup, buckling his seat belt had become an effort. No one imagined the problem with the boy’s right arm was the result of a tumor. His parents took him to their local doctor, who quickly sent them to St. Jude.

“None of us had heard of St. Jude, and initially I was kind of excited even though my parents were worried,” Alsup says. When they arrived and learned that the hospital would take care of almost all their needs, the family realized that St. Jude was completely different from other hospitals.

Alsup underwent four months of chemotherapy to treat osteosarcoma, a bone tumor. But although the tumor did not grow larger, it did not get any better. The next option was amputation.

“I was pretty prepared for the news,” Alsup recalls. “St. Jude had been sending an osteosarcoma patient, who also had his arm amputated, to talk to me while I was going through chemo. My parents came into my room before I went to bed one night and told me. I was not that upset. I cried more when they told me I was going to lose my hair.”

Despite the impending amputation, Alsup laughed and joked with staff on his way to surgery. “As a kid, I understood I had

to go through this to get better,” he says. Surgery was followed by more chemotherapy to make sure the tumor was gone. “It felt awkward at first to not have my right arm, but I had asked so many questions beforehand that I was ready to just jump in and do things,” Alsup says. “I was a big swimmer, and I even started to play baseball, which I didn’t do even when I had both arms.”

Alsup completed his checkups at St. Jude and pursued a communications degree in college. After helping the hospital as a guest speaker, intern and volunteer, he was hired in the ALSAC Communications department. “When I am in the hospital working, I still see nurses who took care of me,” he says. “I can tell it makes them excited to see me doing well.”

Alsup says there is nothing he will not try to do. “People choose how things affect them,” he says. “I am not going to let cancer define who I am.”

**To read stories about some other patients who now work for St. Jude, visit the hospital’s Web site at [www.stjude.org/pts2emps](http://www.stjude.org/pts2emps). ●**



BY JOE HANNA

A longtime friend of hospital founder *Danny Thomas*, *RICHARD C. SHADYAC* has led the hospital's fund-raising organization to scale new heights. *St. Jude* children have been the beneficiaries.

# Just *Climb* the Stairs

FOR NEARLY 13 YEARS, Richard C. Shadyac has walked into his office as chief executive officer of ALSAC, the fund-raising arm of St. Jude Children's Research Hospital, and gone to work to help the hospital accomplish its mission of finding cures and saving children. And every morning, he gets a good look at why he is there.

It's easy to see how Shadyac can remain focused on the task at hand. His office is filled with photos of patients who survived—and some who did not. Shadyac's window also faces the campus of St. Jude, which sits just across the street from the ALSAC headquarters.

"My office is full of the pictures of my children," he says, "because I love them ... and that's what this institution is all about. As long as you can keep your mind focused on what we are all about, you'll be successful."

## First steps

Shadyac has known his share of success as the head of ALSAC, a post he will retire from June 30.

During his tenure, hospital needs increased dramatically, forcing ALSAC to raise the money needed to fuel a billion-dollar expansion and to fulfill the hospital's mission.

When Shadyac became CEO in 1992, fund-raising revenues hovered around \$100 million. In fiscal year 2005, revenues are expected to reach \$450 million. Today, the hospital costs more than \$1 million a day to operate, a far cry from the \$250,000 a year that Shadyac, Danny Thomas and the original ALSAC fund-raisers had to raise in 1962.

"When I took over as CEO, we had a few dollars in the bank, and we were paying off all our bills. We began a concerted effort to expand our fund-raising," Shadyac says.

To do that, the new CEO began making a series of changes that would reap benefits for the organization. He created the Gift Planning department to work with donors who are interested in leaving estates or planned gifts to St. Jude. "We have so many wonderful donors who leave us in their wills that you have to have a professional staff to handle the

matters," he says. "I take great pride in saying that I set up that organization."

He also established the Donor Services department so that donors could easily speak to helpful St. Jude representatives, a reflection of his philosophy of putting donors first.

But for Shadyac, the biggest challenge occurred soon before he took the position: In February 1991, his close friend Danny Thomas died.

## Moving on

As the force behind the hospital's fund-raising efforts, Thomas left behind one of the greatest humanitarian legacies in history. Now Shadyac was faced with the daunting task of not only continuing to raise funds for St. Jude, but increasing those funds. And he had to do it without the hospital's most visible fund-raiser and champion.

"My predecessor [Baddia J. "Bud" Rashid] had Danny Thomas to exhibit to everyone," Shadyac says. "Danny would go to all these events and speak, and he would literally light up a room. And I

ST. JUDE BIOMEDICAL COMMUNICATIONS



Under Richard Shadyac's vibrant leadership, fund-raising revenues climbed from around \$100 million in 1992 to an expected \$450 million in fiscal year 2005. Today, hospital operations exceed \$1 million a day.







asked myself, ‘What are you going to do? You don’t have Danny.’”

The answer to his question came in an epiphany while he slept. “I woke up and I said, ‘The children and the families. That’s what you’re going to do.’”

Shadyac created a talk-show format program called “Meet the Patients,” which he began to host at conventions and corporate meetings. The program allowed families to share their stories about St. Jude. “These are people who have lived the experience,” Shadyac says.

### Ever upward

Though Shadyac is stepping down as CEO, he is not stepping down from St. Jude. He will return to the ALSAC/ St. Jude Boards of Directors and Governors, where he served for many years before taking on the full-time job

of running ALSAC. “I hope that people think I did a good job,” Shadyac says. “I hope that they feel that I gave it my best. And I want them to remember how much I love the children.”

Many members of the Board believe that ALSAC and St. Jude would not be where they are today without Shadyac. He exemplified Thomas’ dream of providing hope to children who seemed to have none, says Joseph Shaker, former chair of the ALSAC Board of Directors.

“When you say Danny Thomas, the next words you say are Dick Shadyac,” Shaker says. “You can’t get any closer to living the legend of Danny Thomas than through Dick Shadyac.”

Says St. Jude Director William Evans, PharmD, “Dick Shadyac is a unique person by many measures. He was a friend and colleague of Danny and shared his dream from the beginning. He

invested his all into raising funds so the hospital could become even greater than the year before. He motivated his staff to achieve their best through his own dedication, and he worked tirelessly because of his love for the kids and their families. He may be retiring, but he will be working for St. Jude forever, and we are all fortunate for that.”

In his stead, John Moses, former chair of the St. Jude Board of Governors, will become ALSAC’s fifth CEO. Shadyac believes Moses will lead ALSAC and St. Jude to even greater heights.

“John is a good man,” Shadyac says. “He has a good heart and a good mind. I think he will do much, much better than I have done. He has a great organization. He will build on it, like I built on Bud Rashid’s organization. All of the stairs are there; you just have to climb them.” ●

## The Next Steps

In July of this year, John P. Moses will become the fifth man to assume the role of chief executive officer of ALSAC, the fund-raising arm of St. Jude Children’s Research Hospital.

Moses will succeed Richard C. Shadyac, who is retiring after 13 years as CEO.

“Dick Shadyac has taken this organization to levels that nobody could have imagined,” Moses says. “When he took over, we were around the \$100 million range. He has taken us to the \$450 million range.

“I will succeed Dick Shadyac, but no one can replace him,” Moses adds. “He has an unusual set of qualities and characteristics that make him a very special person and uniquely qualified to run one of the greatest fund-raising agencies in the world.”

Moses’ support of St. Jude dates back to the 1960s when he participated in Teen Marches, raising about \$35. After graduating in 1968

from King’s College in Wilkes-Barre, Pennsylvania, Moses earned his law degree at the Villanova University School of Law.

As a young lawyer, Moses was approached by the late St. Jude Board Member John Thomas, a family friend whom Moses called “Uncle Johnny.” Moses began a letter-writing campaign to friends and clients, asking for their support for St. Jude, raising \$8,000 that first year. Last year, Moses’ campaign raised more than \$100,000.

“It’s almost frightening to go from raising \$35 to having to raise \$450 million,” Moses says. “But the hospital does such great work for the kids, and the demands of treating the kids the way they have to be treated increase every day. It’s our moral obligation as the Board of ALSAC and the ALSAC staff to meet the demands of the hospital. Hopefully ALSAC, under my leadership and with the help of Dave McKee (the organization’s chief operating officer) and a superb ALSAC staff, we’ll be able to meet the growth of the hospital.”

# Race of a *lifetime*

One tiny boy and his courageous race against cancer

*Gentlemen, start your engines!*

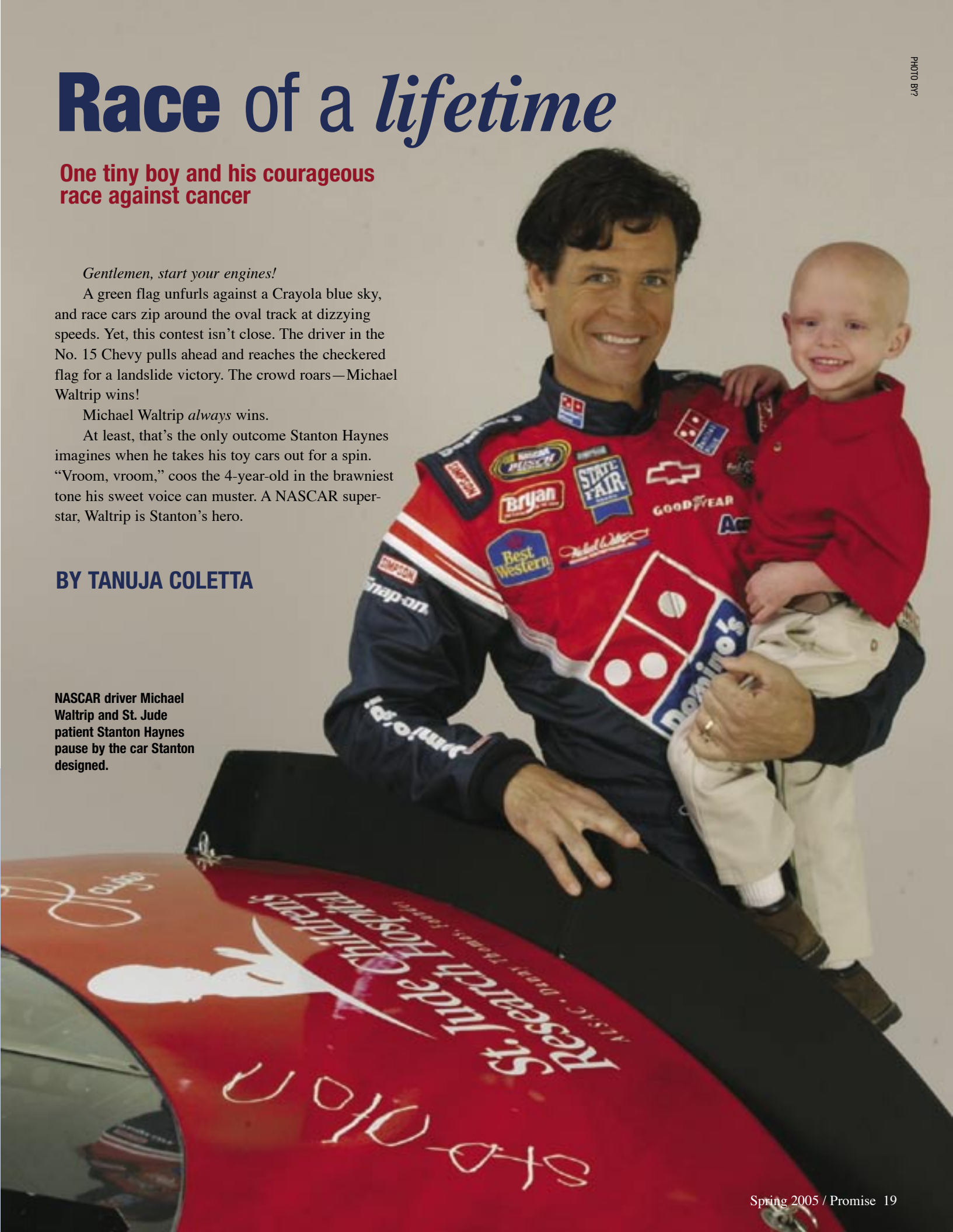
A green flag unfurls against a Crayola blue sky, and race cars zip around the oval track at dizzying speeds. Yet, this contest isn’t close. The driver in the No. 15 Chevy pulls ahead and reaches the checkered flag for a landslide victory. The crowd roars—Michael Waltrip wins!

Michael Waltrip *always* wins.

At least, that’s the only outcome Stanton Haynes imagines when he takes his toy cars out for a spin. “Vroom, vroom,” coos the 4-year-old in the brawniest tone his sweet voice can muster. A NASCAR superstar, Waltrip is Stanton’s hero.

BY TANUJA COLETTA

NASCAR driver Michael Waltrip and St. Jude patient Stanton Haynes pause by the car Stanton designed.





In reality, Stanton is the hero. As he courageously battles a tumor called neuroblastoma, Stanton’s family, his hometown, and even Waltrip are cheering the youngster to victory. His pit crew—the doctors and scientists at St. Jude Children’s Research Hospital—are helping him at every leg of the race.

## On the speedway

Four years ago on Valentine’s Day, Jeff and Tina Haynes looked into their newborn’s eyes and fell in love all over again. It didn’t take long for Stanton to curve his tiny red lips into a grin and charm the socks off his parents and his older brother, Hayden. The couple was ready for a simple life built around the two things that mattered most to them: family and faith.

However, in 2003 when Stanton was just shy of his second birthday, their lives changed. “We went from planning our futures to living day by day, moment to moment,” Tina recalls. “That’s when we started this roller coaster ride.”

The journey began when they noticed Stanton’s eyelids and the area around his eyes change color; they also felt a mass near his stomach. Stanton’s pediatrician suspected neuroblastoma, a common solid tumor in children. A CAT scan backed up her hunch. “It’s like someone took my heart out and stepped on it,” Tina says. “You always think it happens to other people, but this is my baby.”

Despite their anguish, Tina and Jeff, longtime St. Jude supporters, had no doubt about their next move. “I want him at St. Jude, and I want him there now,” Tina said.

They soon learned their son had stage IV neuroblastoma with the primary tumor on his adrenal gland, above his kidneys. The cancer had also spread to the bones in his arms, legs, back and skull, as well as to his bone marrow, the tissue in bones that produces blood cells.

“This was the worst-case scenario we could have dreamed of,” Tina says.

Six rounds of chemotherapy, surgery, radiation and a transplant of Stanton’s own stem cells cleared the disease.

However, Stanton was not out of the woods, yet.

## Big decisions

Research performed at St. Jude has helped boost neuroblastoma’s survival rate from 10 percent in 1962 to 55 percent today. Investigators are trying to find what causes neuroblastoma cells to form in the first place.

While infants seem to respond well to initial therapy, patients older than a year with advanced disease progression have a 70 percent chance of relapse. Nearly two-thirds of neuroblastoma patients fall into this category.

“The disease usually responds to initial treatments, but always seems to come back in certain patients,” says Stanton’s physician, Wayne Furman, MD, of St. Jude Hematology-Oncology.

Sure enough, Stanton’s cancer relapsed.

“That’s when we really had some big decisions to make, none of which came without lots and lots of prayers,” Tina says. The couple has relied on each other, their family, parents of other patients and St. Jude staff members for support. Stanton has been their biggest inspiration.

“He’s such a trooper,” Tina says. “He’s been battling this nasty disease for most of his life and understands that he’s sick; yet somehow, he’s still full of love.”

## Winning design

“Daddy’s gonna love this,” Stanton proclaims confidently as he puts the finishing touches on his masterpiece: a white sheet of paper with yellow and purple scribbles. It’s a tribute to his dad’s favorite football team, the Louisiana State University Tigers.

Stanton slides the paper under his hospital room door and watches through the window for his dad’s return. As Jeff rounds the corner, he picks up the paper, eyes the artwork and beams a broad smile to his son that leaves no doubt Stanton’s proclamation was correct.

It isn’t the first time Stanton’s coloring has had such an effect.



LAURA HAJAR

**Stanton and his brother pooled their artistic skills to determine the color scheme of the No. 99 Michael Waltrip Racing Busch Series car.**

Last year, Domino’s Pizza began a three-year partnership with St. Jude and announced its primary sponsorship of the No. 99 Michael Waltrip Racing Busch Series car as part of its efforts to raise funds for the hospital. Domino’s invited St. Jude patients to take part in a coloring contest to determine the car’s color scheme.

“Stanton and his brother’s design caught my attention right away,” Waltrip says. “As soon as I saw the pepperoni pizza slices around the Domino’s logo on the hood and on the sides of the car, I knew we had a winner.”

The Haynes family flew to North Carolina for the car’s unveiling, and Stanton and Waltrip have since become fast friends.

“We weren’t even big NASCAR fans before this, but now Stanton is his No. 1 fan,” Tina says. “Michael has gone out of his way to make Stanton feel special, and that has meant so much to us. Who would have ever thought that a coloring contest would end up this way?”

## Lessons from Stanton

An experimental therapy that made



LAURA HAJAR

**Stanton clowns around at a Memphis restaurant with his parents and some of his St. Jude buddies, Emma Grace Hampton (with pacifier) and Jaden Brunnemer.**

Stanton radioactive for three days failed to improve his condition. Even 72 hours of high-dose chemotherapy has not been able to stop Stanton’s neuroblastoma cells from spreading.

Stanton’s parents are still praying for a miracle. In the meantime, however, Tina

and Jeff look at Stanton and know that they already have a winner.

“In such a short time, he has touched so many people and has taught us what love and faith truly mean,” Tina says. “He takes life day by day, and he teaches us to be thankful for all that we’ve got.”

# Hometown heroes

The New England Patriots may be NFL champions, but thanks to Stanton Haynes’ hometown, all kids at St. Jude Children’s Research Hospital were winners on Super Bowl weekend.

The people of northwest Louisiana helped raise a record-breaking \$509,179 during the 29<sup>th</sup> annual Minden St. Jude Auction in February. With a population of 13,000, Minden lays claim to raising more money for St. Jude than any other city per capita—\$40 per person. The city was named the St. Jude Volunteer Community of



KRISTI RICHIE, MINDEN PRESS-HERALD

the Nation in 2001 and has donated more than \$4 million to St. Jude since 1977.

“Minden is not a thriving metropolis, but people here do open their hearts and their pocketbooks, especially to help St. Jude,” says Laura Hollingsworth, an auction organizer. “We seem to have had more than our share of kids who are patients at St. Jude.”

The auction began on the radio and has grown to become a four-day telethon and raffle that is broadcast on the local cable station. Louisiana even moved the state chili cook-off to Minden for the event.

Auction headquarters—the Minden Civic Center—is the place to be Super Bowl weekend, says Hollingsworth. “It’s our biggest event of the year.”

While the big prizes at this year’s Mardi Gras-themed auction included a 2005 Lincoln Navigator and diamond necklace, items in years past have included petrified dinosaur dung and emus. “We get a little bit of everything, but that’s part of the fun,” Hollingsworth says. “It’s all for such a great cause. Every child is an inspiration. They give us even more reason to work hard to help St. Jude find cures.”

**High school students helped raise a record-breaking \$509,179 during the annual Minden St. Jude Auction in February.**





PHOTOS BY ANN-MARGARET HEDGES

# Smoke Signals

Lisa and her husband are both career smokers; each exceeding a pack a day for more than 15 years. One of their daughters has asthma; Lisa's youngest son, age 7, is battling a soft-tissue tumor called rhabdomyosarcoma. Until a few months back, Lisa didn't think twice about lighting up in front of her children—at home, in the car, anywhere the need struck. She didn't realize the dangers of secondhand smoke to her children, especially her son in treatment.

## Smoke screen

When she saw parents of St. Jude patients smoking in front of their children, Vida Tyc, PhD, of Behavioral Medicine was

BY VICTORIA TILNEY McDONOUGH

distressed. Tyc learned that 48 percent of newly diagnosed St. Jude patients live in homes with at least one smoker, a statistic consistent with the national average. She began designing a study to reduce these patients' exposure to secondhand smoke.

"No one had thought to conduct a study like this," Tyc says. "The assumption was that parents who had children with cancer wouldn't smoke in front of them, or would understand the heightened dangers of exposure to environmental tobacco smoke (ETS), or secondhand smoke."

Many studies have been conducted with families of asthmatic children, but this is the nation's first protocol to focus on parents of cancer patients. Children with cancer are already at risk for developing second cancers because of treatment-induced

## Many studies have been conducted with families of asthmatic children, but this is the nation's first protocol to focus on parents of cancer patients.

and genetic predispositions. Continuous exposure to high levels of secondhand smoke may increase their health risks even more.

Tyc's five-year study compares two groups for 12 months. The first group receives the information and advice usually given to parents about secondhand smoke. The other group takes part in a new program of education and intervention. The study is open to both smoking and non-smoking parents, as long as at least one adult in the household smokes in the patient's presence.

"We want to see if the smoking patterns of parents change throughout their child's treatment," Tyc says. To do this, she and her colleagues created questionnaires, counseling sessions and education programs addressing such topics as tobacco knowledge, behavioral changes, social support, perceived risk, relaxation and stress management.

## Cold turkey

"This is not a smoking cessation study," emphasizes Diane Brand, RN, of Behavioral Medicine. "It is a study to modify parents' smoking behaviors in the presence of the child and reduce exposure in the child's environment. We hope that by addressing exposure issues, we will indirectly affect the parents' behaviors and perhaps promote some attempts at quitting, but that is not the main goal."

Most participants say it is too stressful to concentrate on quitting while dealing with children undergoing cancer treatment. But some parents have done just that.

"We had a single mother who was very motivated," says Brand. "Initially, she was reluctant to participate in the study.

But once she started filling out the questionnaires and realized how much she was actually smoking in front of her child, she decided to quit altogether. She met her goal two months ahead of schedule. She is one of our success stories."

## Setting goals

Researchers are using parental reports to determine the effectiveness of a behavioral intervention as compared with no intervention.

"Over the months, we develop a rapport with parents and are there to help them set goals—like smoking fewer cigarettes a week, not smoking in the car in the presence of the child or learning how to be firm with relatives about not smoking in front of the child," says Brand. "So far, we have found that the parents are fairly honest and accurate in their reporting and are increasingly so as they learn more and the trust builds."

The accuracy of their reporting is checked against a biological marker. If the parent and child agree, the child's urine is tested for cotinine, a breakdown product of nicotine. Just being in a room with a smoker will increase the level of cotinine in a person's urine.

Another goal of the study is to examine whether a change in tobacco exposure affects short-term health outcomes for the patient.

"With this intervention to lower ETS exposure, what we are truly addressing are the health benefits for the child who has cancer," says Tyc.



When walking the corridors of St. Jude, Diane Brand, RN (left), and Vida Tyc, PhD, are often approached by parents in the study who want to share their progress in keeping their children safe from secondhand smoke.

## Fresh air

Before Lisa agreed to participate in the study, she knew that smoking was bad for her children, but she didn't know how bad it was. Since participating, neither she nor her husband smoke in the house, in the car or in front of the children. Relatives and friends are asked to step outside to smoke.

"We are learning to do things like suck on candy or get involved in an activity if the kids are around and the need to smoke is there," says Lisa.

"The hardest part is knowing you can't have a smoke when the kids are there. The best part is knowing that not smoking is making them a lot healthier. These are my kids; I should have done this a long time ago." ●



# Perspective

## Pyramids? Pshaw!

Hollywood director, screenwriter and producer Tom Shadyac  
ponders the monumental achievements of his forebears.



Like his father, his uncles and Danny Thomas before him, film director, screenwriter and producer Tom Shadyac has an eye for creating success, especially when it comes to St. Jude.

My people, the Lebanese, proudly lay claim to a number of notable cultural accomplishments. In fact, they usually lay claim to many more than are actually true. We did *not* build the pyramids, as my uncles have long insisted. We *did* give the world arithmetic, Kahlil Gibran, hummus, tabouli, and half of Salma Hayek. But nothing—not arithmetic or even Salma herself—compares to our greatest achievement, St. Jude Children’s Research Hospital.

Back in 1958, a Lebanese comic named Danny Thomas gathered his friends for a meeting. Now, if you know the Lebanese, they gather for just about anything—to talk about who’s marrying whom, whose daughter’s dating whose son, whose brother is mad at whom....

(And trust me, there’s always somebody mad at somebody!) But this gathering was different. This was the first step in the fulfillment of a promise: a solemn pledge made by Danny to the patron saint of hopeless causes, St. Jude himself (not Lebanese; sorry uncles...).

Danny’s goal was seemingly impossible: He wanted to start a free hospital and while he was at it, cure childhood cancer. “No child should die in the dawn of life” was Danny’s mantra. At that time, more than 96 percent of children diagnosed with ALL, the most common form of childhood leukemia, died.

Now, the Lebanese are a proud people, and to get them to do something, all you have to do is tell them that they can’t. For the next several years, my father,

BY TOM SHADYAC

Richard Shadyac; my uncles Bud Rashid, Ed Soma, Mike Tamer; and many others traveled the country, knocked on doors—heck, knocked down doors—whatever it took to make this impossible dream real. And in 1962, St. Jude opened its doors for the first time.

Since the Lebanese did have a hand in inventing math, let’s see how all that work has added up. St. Jude now has 60 inpatient beds, and they treat 180 outpatients daily; their budget is in excess of \$1 million a day; they’ve treated children in all 50 states and 80 foreign countries and presently have about 4,700 patients in active status. No patient, not a single one, has ever paid for treatment. And, oh yeah—about that goal of curing cancer? Thanks largely to research pioneered at St. Jude, now 85 percent of children with ALL live.

So, when talking about great cultural accomplishments, don’t forget Danny’s dream. And to any of my uncles out there reading this, you can let go of the idea that we built the pyramids. We built something even better...an extraordinary place of joy and caring, love and compassion, hope and healing known as St. Jude Children’s Research Hospital. ●

*Director, screenwriter and producer Tom Shadyac is the son of ALSAC Chief Executive Officer Richard Shadyac (see page 16 for related story). Tom’s distinguished list of film credits includes Ace Ventura: Pet Detective; The Nutty Professor; Liar, Liar; Patch Adams; and Bruce Almighty.*



In January 2005, country music artists (such as Randy Owen of ALABAMA, top, and Buddy Jewell) visited with St. Jude patients and mixed with more than 800 radio representatives during the Country Cares for St. Jude Kids® Radio Training Seminar. After the three-day event, the attendees headed back to their communities to prepare for radiothons at their stations. The Country Cares program has raised more than \$225 million for St. Jude since 1989.



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

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