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Journey to St. Jude page 17



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 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 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

omise

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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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A publication of St. Jude Children's Research Hospital

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Perspective

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On the cover: St. Jude patient Hannah Lufiyele (see article, page 17). Photo by Laura Hajar.

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Highlights

Gyrating genes

St. Jude investigators have discovered numerous genes that alter their level of activity in characteristic patterns in response to specific chemotherapy treatments. The genes were identified in the leukemia cells of children undergoing chemotherapy for acute lymphoblastic leukemia (ALL).

"While this study's findings occurred in children being treated specifically for ALL, these findings serve as a paradigm for a wide variety of cancers in children and adults," said William Evans, PharmD, scientific director and senior author of the study, which appeared in the May 2003 issue of Nature Genetics.

No butts

A St. Jude counseling program is the first of its kind to show success in reducing future intentions to use tobacco among pre-adolescents and adolescents who survived cancer.

Some adolescent cancer survivors are vulnerable to developing heart and lung disease or cancer in the future. Study participants exhibited improved understanding of the dangers of smoking, heightened perception of vulnerability to health risks posed by tobacco

and increased stated intention not to smoke. Vida Tyc, PhD, of Behavioral Medicine, led the research, which was featured in the April 2003 issue of the Journal of Clinical Oncology.

Job juggler

St. Jude scientists have discovered how an enzyme called E1 performs a rapid-fire, three-part chemical makeover of a protein that helps control some of the human cell's most fundamental biochemical processes. The enzyme uses two parts of its structure to juggle four molecules and complete three different reactions.

The discovery was made by Brenda Schulman, PhD, of Structural Biology and Genetics/Tumor Cell Biology, and Helen Walden, PhD, and Michael Podgorski of Structural Biology. The finding could lead to insights into the control of cellular functions at the core of health and disease. The study appeared in the March 2003 issue of Nature.

Tomorrow's internet

Mega magnet

The St. Jude Hartwell Center for Bioinformatics and Biotechnology has established a new Internet connection

cancer and infectious diseases that affect children.

to link the hospital's scientists to the next-generation Internet, termed "Internet 2" or "I2." A fiber optic connection through The University of Memphis' FedEx Technology Institute will link the two institutions and provide data transmission speeds of 100 million bits per second. I2 is only accessible by educational and research institutions and provides a network environment free of commercial traffic. It is engineered to support highperformance research applications.

Muscle maker

Investigators at St. Jude have discovered that a protein causing mature cells to commit suicide also helps primitive muscle cells called myoblasts to fuse, allowing them to develop into skeletal muscles. The finding of this unexpected new role for the protein, called FKHR, suggests that future research might offer clues to how mutated forms of this molecule cause a form of muscle cancer in children

Gerard Grosveld, PhD, chair of Genetics/Tumor Cell Biology, led appeared in a March 2003 issue of

In a crisis, the world turns to St. Jude

WHEN threatened with glob al panic about SARS and a deadly influenza outbreak earlier this year, the world's medical and scientific community turned to the expert: Robert Webster, PhD. He and his colleagues at St. Jude Children's Research Hospital immediately sprang into action.

They haven't stopped running since.

In February, the World Health Organization (WHO) announced that a lethal strain of influenza virus known as H5N1 had emerged in China and that a global epidemic might occur. In 1997, H5N1, or the "bird flu," had arisen in the Hong Kong poultry markets and moved into humans. The virus killed a third of the people it infected. A larger outbreak was prevented by the slaughter of all Hong Kong poultry. For almost six years, WHO scientists have been stymied in their efforts to create a vaccine against that strain of H5N1. "This is potentially one of the most lethal viruses that may have gone into humans and still we don't have anything to protect against it," says Richard Webby, PhD, of St. Jude Infectious Diseases.

But recently members of Webster's laboratory created a process called reverse genetics that is revolutionizing vaccine production. By tinkering with a virus' genes, St. Jude scientists can create a new strain that can be used as the master seed for vaccine manufacturing. "We are now at the stage where we can make any influenza virus our little heart desires," says Webster, who directs WHO's U.S. Collaborating Center at St. Jude. The center is the world's only laboratory designed to study the transmission of animal viruses to humans.



called rhabdomyosarcoma.

St. Jude recently took delivery of one of the world's most powerful magnets, which will help the hospital's scientists determine the atomic structure of complex biological

in Karlsruhe, Germany, to the United States and was set in place in a specially

designed room in the Danny Thomas Research Center on a cushion of air. The

shielded 800 MHz NMR spectrometer, which contains approximately 150 miles of

the central United States. The instrument will produce a field almost 350,000 times

that of the Earth's natural magnetic field and will provide unprecedented views of the

molecules of life, and how their disruptions lead to human disease. After waiting 18 months for the instrument's delivery, scientists in the St. Jude Structural Biology department are poised to apply the new technology to ongoing research focused on

"superconducting" wire, is super-cooled to -450 F. Although St. Jude already had two smaller, state-of-the-art NMR spectrometers, this is the first instrument of its type in

molecules. The 15,000-pound NMR spectrometer was air-lifted from its manufacturer

the research team. The findings The EMBO Journal.

WHO sent samples of the new H5N1 virus to Webster's lab In February. There, Webby, Daniel Perez, PhD, and other St. Jude scientists worked around the clock to create the experimental vaccine. The task was completed in three-and-a-half weeks. In the past, the process would have taken months or years. "It was strange,"

says Webby, "to come to the lab at 4 a.m. and find you are the third person there." The St. Jude vaccine is currently undergoing testing by scientists in Hong Kong, London and the Centers for Disease Control and Prevention in Atlanta, Georgia.

When another virus began wreaking havoc around the globe-severe acute respiratory syndrome (SARS)-officials again turned to Webster for assistance. In April, he was one of three international experts to attend a summit in Hong Kong to discuss emerging infectious diseases. "SARS is only the most recent

of the so-called emerging infections," Webster said at a press conference after his return. "There are thousands of viruses out there, ready and willing to move across into another host." He has warned the United States and Asia to rebuild public health infrastructures so that those countries can respond quickly to emerging infections.

In the midst of crises, discoveries, consultations and collaborations, Webster and his colleagues have fielded dozens of interviews from the press, resulting in news stories around the world.

Where and when will the next infectious disease emerge? No one knows. But when the time comes, researchers at St. Jude will be ready to meet the challenge.

A St. Jude team that included Robert Webster, PhD, and Richard Webby, *PhD*, *recently* worked day and night to create an influenza virus vaccine in weeks instead of years.

Breaking the Sound barrier

By Lois M. Young

Life-saving treatments cost Bryce Cherry part of his hearing. Several St. Jude researchers are looking for ways to prevent hearing loss in patients and millions of others who are affected.

When the doorbell rings, 3-year-old Bryce Cherry comes running, followed by his little brother, Blake. As soon as the door opens, Bryce hears Maisy the mouse on television and speeds back to the living room. Blake calls his brother's name, and Bryce chases him around the room. Bryce listens as his mother asks him to go to the playroom. He nods, and then is distracted by something more interesting—the sound of a cassette tape recorder.

Bright blue hearing aids are the only sign that Bryce is challenged by a hearing deficit. At an age when most children learn dozens of new words every day, Bryce has lost 60 percent of his high-frequency hearing. But his mother, Kristi, is not upset because the alternative is unthinkable. Less than a year ago, Bryce was being treated for cancer at St. Jude Children's Research Hospital.

"You get to a point where you don't take any day for granted," Kristi says. "We feel so lucky to have him with us."

When Bryce was 9 months old, Kristi and Britt Cherry started noticing something wrong with one of their son's eves. A CAT scan and ultrasound revealed tumors in Bryce's head and abdomen. The diagnosis was stage 4 neuroblastoma.

The next day the couple took Bryce to St. Jude. That week he began six months of treatment including chemotherapy, radiation and a bone marrow transplant. He was given a 30-to-50 percent chance of survival.

Sounds of silence

One of the most successful drugs for treating neuroblastoma is cisplatin. Unfortunately, the drug can cause hearing loss, as it did in Bryce's case. Cisplatin is also used to fight other cancers, such as medulloblastoma, a type of brain tumor.

Radiation to the head can also sometimes lead to hearing damage, so children with brain tumors are more likely to suffer hearing loss than other patients who receive cisplatin. In 2001 St. Jude researchers published promising survival rates for a medulloblastoma scientific treatment plan after its first four years-90 percent for standard-risk patients. But they also found that 30–50 percent of the patients were developing severe hearing loss that required hearing aids.

"At young ages, hearing is so important for language development, social development and learning, that this is a huge issue for us," says Maryam Fouladi, MD, of St. Jude Hematology-Oncology. "Now that we have many patients surviving long term, we can work on trying to avoid these debilitating side effects."

Researchers have now added a new drug, amifostine, to the medulloblastoma treatment plan. The drug is supposed to protect normal cells from the damage of chemotherapy. This is the first project to study amifostine's effect







Maryam Fouladi, MD, of St. Jude Hematology-Oncology meets with a St. Jude patient who has experienced a hearing loss as a result of treatment. Fouladi hopes a new drug, amifostine, will help children avoid hearing deficits when undergoing chemotherapy. This is the first project to study amifostine's effect on children who have a high risk of hearing loss.

on children who have a high risk of hearing loss. St. Jude researchers will compare patients enrolled in the medulloblastoma study after 2000 with those treated during the first four years of the study to see if the rate of hearing loss decreases. Fouladi hopes to have preliminary results about amifostine soon. "If we can show that this drug is effective, then it could potentially go into any treatment plan that uses cisplatin," she says.

Hearing the call

Brain tumors, certain antibiotics and diuretics can also affect hearing in



cancer patients. St. Jude audiologist Nicole Robbins helps patients deal with hearing loss no matter what the cause. The hospital also offers speech therapy services and helps parents find services in their communities.

When a patient like Bryce Cherry has a hearing loss, he receives the best digital hearing aids available, custom fit for comfort. "These newer digital hearing aids are so much better than the old analog type," Robbins says. "They can amplify just the high-frequency sound that many of these patients can't hear as a result of chemotherapy treatment." Robbins works through the

> <mark>Jian</mark> Zuo, PhD, (ce<mark>nter) o</mark>f St. Jude Developmental Neurobiology has spent the past several years studying the disease process that leads to hearing loss. Zuo discusses his research with (at left) graduate student Xudong Wu and Jiangang Gao, a lab specialist in Developmental Neurobiology.

St. Jude School Program to provide an amplification system for the patient's home school. With this system, a teacher wears a transmitter box with a microphone, and the patient wears a small receiver. The system amplifies the teacher's voice up to 50 feet away—a helpful tool on the playground or a large classroom.

Robbins is encouraged by the work St. Jude researchers are doing to decrease the incidence of hearing loss. "The fact that we are able to look at reducing these side effects means that the cure rates are much better than they were when I started here seven years ago," she says. "But even as an audiologist, I understand that our goal is for the children to have good longterm survival, and that must be the No. 1 priority."

Wired for sound

St. Jude scientists have also been making discoveries about hearing in the laboratory. A team led by Martine Roussel, PhD, of St. Jude Genetics/

Tumor Cell Biology and Neil Segil, PhD, of the House Ear Institute in Los Angeles may have found a link between progressive hearing loss and a gene called $p19^{Ink4d}$ (*Ink4d*). Results of the study, published in Nature Cell Biology, showed that laboratory mice lacking the gene Ink4d soon become hearing impaired. Certain cells in the inner ear that should refrain from multiplying start to divide instead; this action causes the sensory hair cells to commit suicide.

Sensory hair cells set off electrical impulses in nerves that help generate the sense of hearing. Rows of these cells form during embryo development, but do not multiply afterward, so lost or damaged sensory hair cells cannot be replaced. That's why hearing loss in mammals is irreversible. But in the absence of *Ink4d*, sensory hair cells may attempt to divide.

"This work seems to say that later in life this gene is critical in keeping these cells intact," Roussel explains.

The researchers may have discovered a previously unrecognized form of progressive hearing loss, which could explain the slow development of deafness in some individuals.



A person who lacks Ink4d function, or who has *Ink4d* genes that are not very active, might suffer progressive hair cell death and experience hearing loss. This might happen spontaneously, or it might happen because the lack of *Ink4d* makes the person more like cisplatin.

"It might be possible one day to screen a person for susceptibility to hearing loss by measuring the level of Ink4d they have," explains Segil.

Sweet sounds of success

Laboratory studies on hearing loss may positively affect the treatment of cancer patients, but the research also has broader implications. "People often underestimate the huge impact of hearing loss on the general population and the economy," says Jian Zuo, PhD, of St. Jude Developmental Neurobiology. According to the American Speech-Language-Hearing Association, one in two people above 65 years of age have hearing problems, and more than 1 million children in the United States have a hearing loss. One in every 1,000 newborns has congenital deafness.

With these statistics in mind, Zuo has spent the past several years studying the disease process that leads to hearing loss. He and M. Charles Lieberman, PhD, of Harvard Medical School led a team that published their findings in the journal Nature. The study offers proof that the protein prestin, acting as a "motor" in the outer hair cells of the cochlea, is key to the ear's ability to amplify sounds. The cochlea is the part of the inner ear concerned with hearing.

F<mark>rederi</mark>que Zindy, PhD, (a<mark>t left)</mark> and Martine Roussel, PhD, of St. Jude Genetics/Tumor Cell Biology have been studying the link between progressive hearing loss and a gene called p19^{Ink4d} (Ink4d).

Prestin affects how the outer hair cells amplify sounds so that we can hear distant train whistles, rustling leaves and gentle whispers. Before this study, scientists suspected that prestin acted in this way. The research team found that the absence of prestin

susceptible to hair cell loss from traumas such as loud noise or medicines

makes it harder for the brain to respond to sound.

Zuo continues to study how the brain sends signals back to the inner ear to modulate the amplification system. This modulation keeps the inner ear from amplifying sound unchecked—until the rustling of leaves sounds like a cacophony.

Scientists at other institutions are lining up to work with Zuo. "There is a great need in the hearing research field for this kind of collaboration, and these studies prove that St. Jude can be a driving force behind these studies," Zuo explains. "We play a very strong role in the field because we can provide reliable biological models."

Safe and sound recovery

Bryce Cherry's cancer has been in remission (a disease-free state) since June of 2002. "But we still have a way to go," Kristi says. "They say if this cancer comes back it is most likely to do so within 18 months of the remission date."

Although there is still a chance that Bryce might relapse, Nicole Robbins says, "He is one of our success stories." He was at high risk for speech and language problems because he lost his hearing at such a young age. "No<mark>w he</mark> talks up a storm," she says.

Kristi offers hopeful words for Bryce's future: "This has been a difficult experience, but I appreciate the fact that Bryce will grow up knowing about St. Jude and knowing what they did for him. When he goes back for checkups, he will see other kids who have been where he has been. I hope that he'll be a better person for it and that he will see the importance of his life and the reason that God chose to leave him here with us."

With the help of hearing loss research at St. Jude, other patients like Bryce might have a better chance of growing up without a hearing deficit—safe and sound.

Building a better Vaccine

The cholera vaccine developed at St. Jude could someday save the lives of millions of children. Vaccines like this one can now be produced at St. Jude—in the world's only GMP facility located in a pediatric cancer research center.

By TANUJA COLETTA

ore than 2.5 million people around the world die of cholera L each year—yet hardly a handful of those cases appear in the United States. That makes no difference to researchers at St. Jude Children's Research Hospital, where geographical boundaries have never stood in the way of saving children's lives.

This summer, St. Jude will seek federal approval to begin teria do attack, people who are treated immediately with a testing an oral vaccine against cholera. If it proves successspecial concoction of sugars and salts usually survive. But ful, the remedy would hopefully offer lifelong immunity to the disease can persist, spread through contaminated food an illness that seems to target the world's most destitute and water. When clean water is unavailable after catastropeople. phes such as earthquakes, monsoons or wars, explosive out-The importance of the research cannot be overstated. breaks can affect thousands of people in a short time.

"It's sort of like the Holy Grail to a lot of people," says Patricia Flynn, MD, of St. Jude Infectious Diseases. "Finding the vaccine has been hard to pin down so far. A successful vaccine could have huge impact on the number of child deaths from gastrointestinal diseases like cholera." With the opening of a new facility for producing biologic

products, vaccines for diseases like cholera can be developed and produced on the St. Jude campus. St. Jude is the world's only pediatric cancer research center to have a Good Manufacturing Practices (GMP) facility. In addition to the cholera vaccine, this high-tech biomedical workshop will

allow scientists to make highly specialized vaccines and medicines to save the lives of children around the globe.

Worldwide crisis

Cholera is caused by a germ that can wreak havoc in the intestines and cause deadly dehydration from diarrhea and vomiting. Once the Vibrio cholerae bacteria find their way to the gut, they multiply and produce a toxin that causes cells to secrete massive amounts of fluid. The bacteria actually stick to the walls of the intestines and punch tiny holes in the cell membranes. Like an uncapped fire hydrant, the membranes force fluid out instead of keeping it inside the cells. Cholera patients can lose 2 or 3 gallons of fluid a day. Although 90 percent of cholera victims face mild symptoms, the other 10 percent have more severe consequences, including death within hours if not treated immediately. Children are the most vulnerable because they have a critical ratio of how much water they can lose compared to

"While we don't see cholera as significant in the U.S., it's a major crisis for child health worldwide," says Flynn.

Perhaps the greatest tragedy of cholera is that most of the deaths are preventable. Vibrio cholerae tend to wimp out when met with good

hygiene and proper sanitation. Even when the bac-

their weights.

Because of chronic outbreaks, the world is now in the midst of its seventh cholera pandemic, which began in 1961 in Indonesia and spread to other eastern Asian countries, the then-Soviet Union, Iran and Iraq. Cholera invaded West Africa in 1970 and Latin America in 1991. Although no significant outbreaks have occurred in the United States since 1911, national and world health organizations consistently advise travelers to take precautions. The Centers for Disease Control and

Prevention offers this rule of thumb to hungry travelers: "Boil it, cook it, peel it or forget it."

Avoiding cholera isn't easy for residents of countries where the bacteria are common. "Sure, you can treat the dehydration by taking in more fluids, but it doesn't help matters if the water you replace it with is still contaminated," says Flynn. "We also have antibiotics that treat cholera well, but the constant exposure to contaminated water makes that option ineffective, too."

Commercial vaccines are available, and recent oral vaccines have had positive effects. However, these vaccines have not proven effective against all types of cholera; they only offer short-term immunity and sometimes have serious side effects.

Flynn's team of researchers may have produced a solution that sidesteps those problems.

A better way

St. Jude launched its cholera studies in 1999 with the creation of the Children's Infection Defense Center. The center's research focuses on the top four killers of children: pneumonia, tuberculosis, cholera and AIDS. Together these illnesses kill 12 million children each year. The cholera vaccine under study now is aimed at prevention and uses a live-albeit somewhat weak-strain of Vibrio cholerae. "We're getting a better response from this bacterium because it can be genetically modified so that the harmful material can be taken out; therefore, the germ will not cause the disease, but rather provide immunity," says Flynn.

Because the GMP was not yet open, St. Jude sent its modified cholera strains to the Walter Reed Army Institute of Research in Maryland, where large batches of the vaccine were made. Now, St. Jude researchers are thoroughly

The Vibrio cholerae bacteria wreak havoc in the intestines and cause deadly dehydration. These insidious bacteria were photographed by Gopal Murti, PhD, director of Scientific Imaging Shared Resource at St. Jude.

reviewing their methods before moving onto the next step—seeking approval from the Food and Drug Administration. "We don't want to get ahead of ourselves," says Flynn. "We want to be sure that our methods are proper, that we have a clean and pure product and that everything is done in a safe and consistent manner." Flynn hopes to receive FDA approval and begin clinical trials by the end of this year.

The St. Jude vaccine is actually a slurry infused with live cholera bacteria. Healthy volunteers will drink a glass of the concoction and then spend a week at a local hospital, where they will be closely tested to see if they present symptoms like nausea and vomiting.

"A successful patient will be one who can drink the slurry, have no gastrointestinal symptoms and build antibody levels," says Flynn. "We're very hopeful."

Progress over profit

If the St. Jude cholera vaccine is successful, it will eventually be sent to a large pharmaceutical company or other producer to make the massive quantities needed for worldwide consumption. In the future, however, the initial supply of such a vaccine could be made at the new St. Jude GMP facility, a building dedicated to manufacturing highly specialized medicines, vaccines, drugs, proteins, gene-based molecules and other biological products under the FDA's strict guidelines for Good Manufacturing Practices. The facility will also allow for the production of the three-tiered AIDS vaccine currently under development at St. Jude.

"The GMP serves to support the research at St. Jude," says John Coleman, facility director and vice president of St. Jude Therapeutics Production and Quality. "Our purpose is to help with the translation of fantastic research ideas from the laboratories into clinical products that can be used to treat children."

The 64,000-square-foot building was constructed to ensure a totally germ-free environment completely isolated from the rest of the St. Jude campus. The state-of-the-art facility, which features an intricate security system, also houses Biological Safety Level 3 laboratories to accommodate work done with microorganisms that must be specially contained.

"This is a unique building and was built with the federal guidelines in mind from the time we started talking to the architects," says Coleman. "The GMP regulations have a lot of elements involved that not only include how you make the product, but also





Hope Smith of Infectious Diseases picks colonies of cholera for isolation. The colonies will be tested to ensure that they have the right mutations to use in a live, experimental vaccine.

where you make it, how you control the environment that it is made in and how you handle the raw materials and supplies you use in the process. Every step is important."

The GMP puts St. Jude in the unique position to further the research and treatment of rare childhood diseases, many of which are overlooked by pharmaceutical companies because there is little profit in developing drugs for rare diseases and because insurance companies often will not cover costs of novel therapies. Because profit does not drive the work at St. Jude, researchers are able to focus on finding treatments for children by quickly transferring promising discoveries into cures, even when those remedies help a small number of very sick patients.

In fact, the GMP has been designed specifically for small-scale productions. With recent technological breakthroughs that will allow doctors to pinpoint exact treatment for a particular patient, the facility could even produce a single batch of medicine for a specific treatment created for an individual child.

"The one thing that stands out about this facility is that it will be used for a lot of different processes, many of which are still being dreamed up by our researchers," says Coleman. "Because of this, we've made every effort to be flexible. Everything in the processing rooms can be taken out, cleaned and stored, and we can bring in new materials we need for a particular process on a given day or month.

> Who knows where the research will take us in the years to come?" •

In the new GMP facility, St. Jude researchers will be manufacturing highly specialized medicines, vaccines, drugs, proteins, gene-based molecules and other biological products under the FDA's strict guidelines for Good Manufacturing Practices.

Rhythm & Hope: A Family Thing

Spurred by the success of Country Cares for St. Jude Kids[®], urban radio offers a soulful twist to traditional fund-raising programs.

adio personalities often have a way of reaching out to listeners and drawing them in with witty expressions blended with melodious sounds. Many times listeners feel that they are part of one big family. Memphis radio station Soul Classics 103.5 WRBO recently enlarged the St. Jude family by holding "Rhythm & Hope," the first Radio Cares for St. Jude Kids® radiothon for urban radio. During this event, the Memphis community did what any family would do-they pulled together to help "their" children at St. Jude Children's Research Hospital.

St. Jude has enjoyed 15 years of support from the country music industry through its Country Cares for St. Jude Kids[®] radio program. The overwhelming success of that program are right under our noses," says

has paved the way for the industry leaders in Spanish-format radio and other formats within the Radio Cares program such as adult contemporary, oldies, lite rock and now urban radio to increase their involvement with the hospital.

The "Rhythm & Hope" radiothon kicked off with a karaoke pre-event, where the radio station donated a percentage of the proceeds to St. Jude. The radiothon, which raised \$54,329, consisted of two 12-hour days devoted to the fusion of music, patient stories and community appeals. Radio personalities encouraged listeners to join the St. Jude family by becoming Partners in Hope. Celebrities such as Marlo Thomas, Isaac Hayes, George Wallace and John Amos also offered special hospital endorsements through direct call-ins or pre-taped messages. "So often we overlook things that

SETH DIXON

Henry Nelson, program director for Soul Classics 103.5 WRBO. "But as a community it is our obligation to take ownership and support the things that are happening here. Essentially, we are all family, and that's the message I wanted to get through to our listening audience. I think the message was well received."

Hospital fund-raisers predict that Radio Cares program will join the ranks of other radio programs at St. Jude by becoming a nationwide event.

"We are pleased that this radiothon was such a success," said Richard Shadyac, national executive director of ALSAC/St. Jude. "With a track record of 15 years working with other radio formats to raise money for the hospital, we expect that Radio Cares will only increase its level of success in years to come.".

In April of 2003, the best of corporate America, science and Hollywood met the "real" stars-the children of St. Jude.

higher.

Following lunch at Target House, Harvard University Law Professor Charles Ogletree led the CEOs in a dialogue about how St. Jude can move into the 21st century as a business. After a day of learning about St. Jude, invited guests, CEOs and

celebrities attended a cocktail party at the Cannon Center for the Performing Arts. The day was capped by a special concert with entertainment by Robin Williams; country star Lee Ann Womack; the Rev. Al Green, rhythm and blues legend; and singers Josh Groban and Marc Anthony. Commemorating the 40th anniversary of St. Jude, Shower of Stars

Carrie L. Strehlan

Celebrating St. Jude at the Shower of Stars gala were (clockwise from top): actress Natasha Henstridge; singers Nita Whitaker and Josh Groban; singer Marc Anthony; comedian and actor Robin Williams; patient Brenan Rodgers; Phil Donahue; patient Marko Miranda and his mother, Patricia; and (center): the Rev. Al Green and singer Lee Ann Womack.

ST. JUDE CHILDREN'S RESEARCH HOSPITAL recently welcomed more than 100 of the country's top CEOs for a special, intimate look at the hospital.

Christened Shower of Stars, the event had its beginnings back in 1955, long before the hospital was built. Danny Thomas orchestrated that first Shower of Stars benefit to help raise money for his dream-St. Jude. Since that time, Shower of Stars has welcomed legends such as Frank Sinatra, Bob Hope, Jerry Lewis, Elvis Presley and Sammy Davis Ir. In 2003, the list grew longer and the support grew stronger with such celebrities as comedian and actor Jim Carrey, supermodel Amber Valetta, soap actress Deidre Hall, comedian and actor Robin Williams, and actress Natasha Henstridge visiting St. Jude patients and taking the opportunity to learn more about just what the hospital does. Beginning the morning of April 26, a cadre of guests that included Michael Eisner, CEO of Disney/ABC; Terry Semel, chair and CEO of Yahoo! Inc.; Geraldine Laybourne, chair and CEO of Oxygen Media; and Andy Lack, CEO of Sony Music Entertainment Inc. toured the hospital and attended a scientific briefing led by several top scientific investigators at St. Jude. Nobel laureate Peter Doherty, PhD; Scientific Director William Evans, PharmD; Karen Slobod, MD, of Infectious Diseases; Julia Hurwitz, PhD, of Immunology; world-renowned virologist Robert Webster, PhD; and Human Applications Laboratory Director John Cunningham, MD, were among those who discussed the tremendous progress St. Jude has made in the battle against catastrophic pediatric diseases and the continuing efforts to drive cure rates even

was hosted by Marlo, Terre and Tony Thomas and co-chaired by Barry Diller, chair and CEO of USA Interactive; Ann Moore, chair and CEO of Time Inc.; Fred Smith, chair, president and CEO of FedEx Corp.; and Bob Ulrich, chair and CEO of Target Corp. The event raised more than \$4.5 million for the hospital.

members shield their eyes against the brilliant sun as the butterflies soar upward and disappear into the cerulean sky.

The butterfly release is one of many activities that occur during Day of Remembrance. This important day is set aside to honor St. Jude patients who have died during the past two years. As part of the annual event, scores of doctors, nurses and other employees visit with the families at a

ory boxes.

As parents file into the auditorium at St. Jude, some look about with dull, empty eyes; others exude a serenity and grace that comes after emerging from a great struggle. During Day of Remembrance, these individuals unite

Like transitory spirits, colorful butterflies fly toward the heavens (at left) at the culmination of Day of Remembrance events. This year's event included special activities for siblings, who sang, played and made memory boxes and other crafts while their parents attended workshops. Family members attended a reception, where they reminisced with St. Jude employees who had known their children. Siblings and parents also placed flowers in large bouquets during a Day of Remembrance memorial service.

Day of By Elizabeth Jane Walker Remembrance

In spite of heroic efforts, some children still die in the dawn of life. St. Jude helps grieving parents celebrate the lives of those children.

SUNLIGHT gleams off the golden dome of the Danny Thomas/ALSAC Pavilion as 260 family members gather on the lawn of St. Jude Children's Research Hospital. At a word from Chaplain Brent Powell, each family releases a colorful butterfly balloon. Like transitory spirits, the balloons dance toward the heavens. Family

reception, sharing memories and hugs, laughter and tears. Day of Remembrance also includes a memorial service and seminars. Siblings spend much of the day singing, playing and creating memto help one another. "Together we can find strength to go on and live and cherish our sweet memories of a child that forever changed our lives," says Vicky Fairey, whose 16-year-old son, Brantley, died after battling brain cancer.

Parents who have moved through the grief process share their insights with newly grieving families. During one seminar, Paul and Paula Kizer, parents of former St. Jude patient Steve Kizer, reminisce about their St. Jude experience.

"We had heard of St. Jude, but we really didn't know much about it," Paula says, recalling her first trip to the hospital. "On the way down, I was making notes about how much we could refinance our house for; how many cars we could sell. We thought that we were going to get here and they were going to say, 'Well, we need \$50,000 today.' But they didn't take everything that we had; they just took

us. And they were good to us. What a place this is!"

Many parents come to Day of Remembrance asking difficult questions. Fairey poses a response to one of those. "The question now is not 'Why?' but 'What happens now?'" she says. "What do we intend to do with our lives from here on out? Although we did not have a choice in what happened to our child, we do have a choice now in how to handle it."

Tom and Stacy Pedersen lost their 5-month-old son, Matthew, to acute lymphoblastic leukemia. The Pedersens attended Day of Remembrance twice as participants. This time they return to share their observations with others. "The first year," says Stacy, "I got some benefit from the weekend, but I wasn't allowing myself to be helped." But the balloon release the following

Loretta Jackson, mother of former St. Jude patient Lashundra Jackson, comforts a fellow mother at the Day of Remembrance balloon release.

Lessons Learned

During the memorial service at the 2003 Day of Remembrance, Chaplain Lisa Anderson shared the following observations regarding wisdom she has gleaned from St. Jude parents and their children.

Your children have taught me:

- that sickness and suffering happen no matter how old or young we are;
- that having people we love around us makes suffering somehow more bearable;
- that the touch of tiny fingers and sounds of baby giggles is food for my soul;
- that playing and playing and playing is the work of our life;
- that you can see without eyes and you can run without legs;
- that every second we are alive is important, and our impact on this world is not measured in years;
- that the most important lessons can be learned from infants, children and teenagers who never get the chance to grow up.

You parents have taught me:

- that being a parent, grandparent, sister, brother, aunt or uncle is a gift that I should never, ever take for granted;
- that it takes courage to experience life completely in the middle of indescribable pain;
- that faith is something that takes work to understand and strength to define;
- that friendships never end;
- that we are strengthened when we share the journey.

You have shared your children not because you have chosen this path but in spite of it—and it has taught us lessons we could learn in no other way. We will always be grateful, and we will always remember them because they are a part of our hearts and our lives, and they've changed the world that we have lived in. year held special significance. "On the second year when we came to Day of Remembrance, by the time we let the balloons go, I felt like I was setting Matthew free and moving forward," she says.

Heather Durham's 9-year-old son, Jacob, died five years ago. She says the butterfly used as the symbol for Day of Remembrance represents the parent's journey as well as the child's spirit. "What gives the butterfly the strength to fly away is that struggle it takes to come out of that cocoon," she tells participants. "What is going to enable you to come out is the struggle through this grief process. You're growing the courage and the strength in this grieving that you're going to need to continue with your life.

"Give of yourself to others when it's time," she urges bereaved parents. "You'll know when it's time. As hard as it may be, one of the best healing processes is giving of yourself to people who are in need.

"Just remember: pain and suffering will not last forever; hope and love are eternal."•

Journey to St. Jude

Postdoctoral fellow Roderick Hargrove, MD, uses a finger puppet to capture Hannah Lufiyele's attention while Barrett Haik, MD, director of the St. Jude Eye Clinic, examines the tumor on Hannah's eye.

Hannah and her family traveled the world trying to find medical care. Then they found St. Jude. SETH DIXON

By Elizabeth Jane Walker

hen Hannah Lufiyele was born in Harare, Zimbabwe, her parents knew right away that she needed medical attention. Three years and 9,880 miles later, they finally obtained it.

Samuel and Naome Luifiyele's journey has been arduous, paved with prayers and the persistence of devoted parents. When the adventure began, the Lufiyeles had no idea which direction to travel. Propelled by faith, they followed a circuitous route that led them halfway across the globe to St. Jude Children's Research Hospital.

After extensive diagnostic testing, the St. Jude surgical team realized that the mass was a benign tumor that had destroyed the entire eye. The tumor was removed, implants were used to reconstruct the area. A couple of weeks later, Hannah received an artificial eye that matches her other eye exactly.

Family crisis

The Lufiyele family comes from a country that is staggering under the burden of famine, a long civil war and one of the world's highest HIV infection rates. Inflation exceeds 200 percent, and nearly 7 million people are in danger of starvation. When Samuel began his career as pastor of a rural church, he quickly became accustomed to tending to the spiritual needs of a people in crisis. It was a calling he relished.

"There is a lot of polygamy and prostitution in the farming and mining area I was pastoring," he says. "Pretty much every week I was burying two or three people who had died from AIDS. It's a really tough place." Then the Lufiyeles faced a crisis of

their own.

When their daughter, Hannah, was born, neither Samuel nor Naome was allowed to see the child until the following day. When Samuel arrived for his first visit, a nurse greeted him with the words, "Oh, it's you-the father of the blind baby!" Soon Samuel

learned that his lovely daughter was not blind after all, but that she did have a tumor protruding from one of her eyes.

The Lufiyeles were bombarded with advice from all sides. "People were saying, 'Oh you should not be Christians because of this. You should take her to a very good witch doctor," Samuel recalls. "Others either blamed the husband or blamed the wife. So either my wife did something wrong and she was being punished for it, or I did something wrong and I was being punished."

The couple held to their faith and began looking for someone to treat their child. A respected member of the medical community promised the Lufiyeles that Hannah could be cured for 13,000 Zimbabwean dollars. With the help of their church and friends, the couple raised the money. "The doctor said to us, 'Once we treat Hannah, three days later she will be okay and the eye will be fine," Samuel says.

But after the couple paid the fee,

they watched as four doctors argued about how to proceed. "One doctor was saying, 'Why should we take the eye out?' and another was saying, 'Let's take the eye out because they've paid this money," says Samuel.

"They were giving us no options, and there was confusion."

Naome and her husband looked at one another and tacitly agreed on their course of action: "Can we have the baby?" they asked. The doctors returned the child to her parents along with a "refund" of only 1,800 Zimbabwean dollars.

Hamburgers and hope

Believing that they might be able to find treatment in England, the Lufiveles moved there. But they soon encountered another obstacle when they learned that Samuel's job as a missionary youth worker did not qualify him to receive public medical benefits.

Help eventually came from the most surprising source—a chance

Before undergoing an operation at St. Jude, Hannah Lufiyele had a large tumor protruding from her eye. "She had an eye abnormality that had never been described or seen before," observes Haik.

Samuel and Naome Luifiyele wait with their infant son, Jireh Benjamin, while their daughter undergoes an operation to remove the tumor.

meeting in a fast food restaurant. While the wife of an American eye was admitted.

Help at last

or seen before."

After extensive diagnostic test-A bright and active little girl,

ing, the St. Jude surgical team realized that the mass was a benign tumor that had destroyed the entire eye. Haik, Matthew Wilson, MD, and postdoctoral fellow Roderick Hargrove, MD, removed the tumor and the eye, using implants to reconstruct the area. A couple of weeks later, Hannah received an artificial eye that matches her other eve exactly. Hannah is no longer plagued by the discomfort of a large tumor. She no longer has to endure the

ridicule and stares of strangers and acquaintances. Formerly self-conscious

surgeon watched her children play in a McDonalds play area one day, she struck up a conversation with David Lipiate, a missionary who had recently returned from Zimbabwe. Lipiate told Anne Hall about Hannah and her condition. As a result of that encounter, Anne and her husband, Michael Hall, MD, began e-mailing the Lufiyeles. Last fall, the Halls helped finance the Lufiyeles' trip to the United States. With further assistance from the local Lions Club, the Lufiyeles continued their journey to St. Jude, where Hannah

When she arrived in Memphis, Hannah met Barrett Haik, MD, director of the Eye Clinic at St. Jude. "When we first saw her, she had a massive disfiguration," Haik says. "The tumorous mass was coming out between her eyelids. She had an eye abnormality that had never been described

about her appearance, the 3-year-old now spends her days running and playing with abandon.

"Everything has worked out just perfectly for them," observes Michael Hall, who now practices medicine in Iowa and remains in close contact with the Lufiyele family. "They've been very pleased with the care that they've gotten at St. Jude. My wife and I had seen the St. Jude TV programs before, but it makes it a lot more personal when you know some-

Today, Hannah is a happy, active and exuberant 3-year-old. "It is a miracle," says Samuel, of her journey to St. Jude. "And every time I tell this story, my tears just roll down.'

body who's been there. I'm a firm believer in that place."

Because they are currently exploring career and educational opportunities, Samuel and Naome are unsure where they will end up—in the United States, England or Zimbabwe. But regardless of their destination, the Lufiyeles are thankful that their journey took them to Memphis and St. Jude Children's Research Hospital.

"It is a miracle," says Samuel. "And every time I tell this story, my tears just roll down."•

DéjàDéjà Vu

St. Jude saved Tricia McCarver's life back in 1984. When her daughter was stricken with cancer in 2002, Tricia knew exactly where to turn.

By Elizabeth Jane Walker

Fifteen-year-old Tricia Smith just knew. Call it intuition; call it a hunch; call it an educated guess. But the young athlete knew that something was wrong. As the pitcher on a softball team, Tricia was immediately aware when she began losing strength in her arms. Then came the shortness of breath, lack of appetite and frequent bruising.

"I walked in and told Momma one day, 'I have cancer,'" recalls Tricia. "Momma said, 'Excuse me?'" and I said, 'I have cancer.'"

When a mysterious bump had arisen two years earlier, Tricia's doctor determined that she had pulled a muscle. Sure enough, the lump eventually disappeared. But in 1984, shortly after Tricia's conversation with her mother, another bump arose on the girl's chest. Because Tricia played basketball, racquetball, softball and volleyball, her doctor again assumed that she had pulled a muscle or had developed arthritis. "He wouldn't do any biopsies or X-rays because he said I was too young to be exposed to them," recalls Tricia.

The new lump grew with alarming speed. A week later, Tricia accompanied her father to one of his medical appointments. "Daddy's doctor wouldn't even look at him," says Tricia, "because when I walked in, the tumor in my chest was so huge that it stuck out of my shirt." The physician immediately hospitalized Tricia, and found that she had advanced Hodgkin disease, a cancer of the lymph nodes.

"A surgeon walked into the room and told Daddy, 'She has cancer. She has two weeks to live,' says Tricia.

In spite of that dire prediction, Tricia and her family traveled from their home in the Appalachian foothills to Memphis, where she entered St. Jude Children's Research Hospital. She underwent aggressive therapy that included radiation and debilitating chemotherapy. "The chemotherapy made me so sick," remembers Tricia. "I was sick for eight hours straight, and then I began losing my hair."

After one interminable year, the disease went into remission. Tricia eventually finished high school, attended college and had two daughters. She and her husband, Tim McCarver, didn't worry about the girls' health, because doctors had assured them that Hodgkin disease did not run in families. Whitney and Brooke inherited their mom's athleticism and competitive spirit. Tricia returned to a lifestyle that revolved around sports—but instead of playing them, she was cheering from the stands.

Then, once again, she got that feeling. Tricia just knew something was wrong.

Double jeopardy

This time, the premonition was about her younger daughter, Brooke. Like Tricia and Whitney, Brooke was an energetic and dedicated softball player. In October of 2001, the normally healthy youngster began having occasional stomach aches and fatigue. The doctor found nothing amiss during subsequent checkups. One day during softball practice in March of 2002, a ball hit Brooke in the face. That night, she had a nosebleed. During the next few days she had several more nosebleeds, of increasing intensity.

"I'll just be honest with you," Tricia told her daughter's physician, "I believe Brooke has cancer." A few minutes later, Brooke began having stomach pains. "Just to ease your mind, we're going to send her over to the hospital and do an X-ray,"

ANN-MARGARET HEDGE

In 1984, Tricia McCarver vanquished advanced Hodgkin disease, a cancer of the lymph nodes. Now her daughter Brooke is fighting a similar battle. said the doctor.

Later that day, Tricia's cell phone rang. Before she answered the phone, Tricia looked at her mother and said, "She has cancer. I've been right for six months now."

Tricia also knew the diagnosis before the doctor confirmed it: Hodgkin disease.

"I want to take her to St. Jude," she told her physician, firmly. "I was a

patient there, and I had two cousins who were patients there. I'd just feel better if we go there and see Dr. [Melissa] Hudson."

Chemo redux

When Tricia arrived at St. Jude, she faced a few more challenges than most parents do. She knew firsthand what her child would have to endureexactly how it would smell and how it would feel. The memories came rushing back when Tricia entered the Medicine Room for Brooke's first chemotherapy infusion. "I couldn't smell any of that medicine without getting sick," says Tricia. Nevertheless, she sat placidly until Brooke had begun her chemotherapy and had become engrossed in a movie. Then Tricia excused herself and went to the restroom. "I was as sick as a dog," she says. "After that, I got over it, because I knew I had to be there for her."

Melissa Hudson, MD, admits that the staff was concerned about Tricia when the family came to St. Jude. "It was stressful for us to see Patricia watching her daughter," says Hudson, who points out that the odds of having multiple cases of Hodgkin disease in one family are extremely rare. Two of Tricia's cousins had also battled acute lymphoblastic leukemia, so Brooke was the fourth person in the family to have cancer.

"Some families might have said, 'Oh, my gosh, another diagnosis of

course."

"But Patricia just said, 'I had it; I was cured, and you can be, too.' She has gone straight through with that kind of attitude, and hasn't let her anxiety or worries affect Brooke's

mother before her.

ball player.

Brooke is an avid soft-

cancer! How are we

going to get through

it?" says Hudson.

Brooke says her mother's experiences have helped her cope with the rigors of cancer therapy. Instead of spending a year in treatment as her mother had done, Brooke only spent four months at St. Jude for her initial therapy. "It helped that I knew what she had to go through, only she had to go through more stuff than I

did," admits the 11-year-old.

Brooke's illness also helped Tricia empathize with her own mother's experiences. "I'm going through what my mother went through 18 years ago," she says. "I actually understand now how she felt."

Tricia also has a new appreciation for St. Jude. "I love everybody up there," Tricia says. "If it weren't for them, neither of us would be here."

Life, cameras, action

Last fall, Brooke thought she was through with chemotherapy and radiation. But in April of 2003, she discovered that her Hodgkin disease had returned. Brooke is currently undergoing additional intensive treatment at St. Jude to eradicate the disease.

The talkative and effervescent girl has her sights set on an acting career, and she is taking her mom's no-nonsense approach toward accomplishing that goal. "Ever since I was 5 years old, I wanted to go to London and be an actress," Brooke says. Last December the Dream Factory financed what Brooke terms a "groovy" week in London, where she toured the Harry Potter set and met the stars of Grease. She quizzed the actors about their career paths and obtained tips for breaking into show business. Now Brooke has a plan: "I'm going to go to college—I don't know which one yet and I'm going to take some foreign languages, and then I'm just going to audition for parts," she says.

Thanks to the care she is receiving at St. Jude, Brooke anticipates a future under the spotlights. Call it intuition; call it a hunch...but she just knows that she's going to be famous someday•

Brooke cuts up with Crystal Holland, *St. Jude radiation therapist.*

Charting the Course

Donors find direction through BY ALICIA H. MATTHEWS

hildhood is not easy for the patients at St. Jude Children's Research Hospital. Every day they fight to overcome obstacles that most children never have to consider...obstacles that force them to mature much faster than normal children.

St. Jude donor Pat Patterson understands all too well what it's like to mature quickly and work to overcome challenges. When he was 18 months old, his mother died, and he was subsequently cared for by his grandfather until the age of 16. That's when he dropped out of school and moved away from home trying to find his way in life.

Patterson's life began to take an upward turn when he moved to Memphis. He began his first job working at an auto store-making \$28 a week. He later got into sales with an independent car dealer where he gained a reputation as a "super car man." His reputation led to an opportunity for him to partner in a used car franchise and eventually own his own car dealership, Pat Patterson Volvo.

Patterson says a turning point in his life was when he met his wife, Dorothy. "I had a pretty nice ship, but I didn't have any rudder," he recalls. "I was going around and around, and she stabilized that ship. She

Pat and Dorothy Patterson have various donations,

helping the children of St. Jude.

was so supportive. She made a difference in what happened to me." Just as Dorothy helped her husband find his way in those early days, the couple later found a route to helping the children of St. Jude through various donations, including a charitable remainder trust.

> "As you get older, you realize people have been supportive of you and you feel compelled to give something back,"

Patterson says. "Everybody benefits from this hospital, and I think when we made the decision to give, there was no better choice than St. Jude.'

helped the children of St. Jude through including a charitable remainder trust.

The Pattersons say that they hope their children and grandchildren will learn from their charitable example. "I wanted to do something while I'm still living and realize that I did contribute something back to life," Patterson says. "There's no question we made a good choice by donating to St. Jude. If our donation helps save one life, we've made a difference."

A charitable remainder trust allows donors to put assets into a trust that will pay them an income throughout their lifetime or for a term of years. At the end of their lives or the term of years, the amount remaining in the trust is then given to the charitable beneficiary.

To learn more about charitable remainder trusts and other ways to give, call the St. Jude Gift Planning department at (901) 578-2081 or toll-free at (800) 830-8119 ext. 2081.

Perspective

All kinds of heroes

By Michael Heisley

I grew up as a big basketball fan. Players like Jerry West, Dr. J., Wilt Chamberlain and Larry Bird kept me glued to my set and made me beg to be taken to the next NBA game. When Michael Jordan joined my home team, the Chicago Bulls, he rose to the top of my list of heroes. Our city united in a

New loom

Michael Heisley and Memphis Grizzlies player Pau Gasol participate in the groundbreaking ceremony for the Memphis Grizzlies House at St. Jude. The Grizzlies have pledged \$5 million toward construction of the \$10 million building. The residence will provide a home-like environment for up to 100 families at a time.

passion that can only be ignited by watching winning basketball night after night.

The fact that my passion for basketball eventually turned into ownership of my own NBA team still gives me

goose bumps. The team is located in Memphis—a place that before the year 2000 I had never visited. Without basketball, I might never have formed a bond with St. Jude Children's Research Hospital.

"Just one visit to St. Jude highlighted the real heroes."

Athletes impress and excite us. While many of them are also fine citizens who contribute to their communities, we look up to them because of their grace, their strength and their ability to perform at an elite level. Just one visit to St. Jude highlighted the real heroes.

people like Danny Thomas. I grew up watching Danny's movies and television shows. I looked up to him. Yet, his legacy goes far beyond the screen.

Real heroes are

He was just one man, yet he believed so strongly in helping others that he founded St. Iude.

Real heroes are the kids of St. Jude who look adversity in the face every day and challenge it; who after experiencing painful treatments comfort their desperate parents.

Real heroes are the staff and volunteers at St. Jude who research and cure, comfort and cry, console and rejoice.

I was struck that the average donation to St. Jude is \$30. Hundreds of thousands of everyday heroes give from their hearts and their hard-earned dollars every year to support research and care for kids.

My passion is still basketball. It thrills me every time our young team pulls out a big victory. Yet, just by reading this magazine you are my hero. Perhaps your company has given millions to St. Jude. Perhaps you are a former patient who raised \$100 through a bake sale. Maybe you save St. Jude \$700 or more every time you donate platelets. Maybe you've not yet given. When you do, you'll be part of a winning team. Victory is ours.

Michael Heisley is majority owner of the Memphis Grizzlies NBA team and the Heico group of companies. Heisley and the Grizzlies have made a \$5 million pledge to sponsor Memphis Grizzlies House at St. Jude, the hospital's first on-campus short-stay facility for patients and families.

St. Jude children and teens were provided with a fun and interactive way to learn about the human body during Child Life's "Inside and Out" week in March. Each day's topic centered around a different system of the body. George Bikhazi, MD, of Anesthesiology, and many other physicians participated in the group activities.