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

“Show me my way in life,” Danny prayed. In return, Danny promised to build St. Jude Thaddeus a shrine. That shrine became a hospital that would treat children regardless of race, color, creed or their ability to pay. This remarkable event also inspired the name of this magazine, Promise.
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Highlights

Rising from the ashes

For the past 11 years, the Wall Street community has held an annual fund-raising dinner called Taste of New York, which has raised more than $14 million for St. Jude. But last November’s event was cancelled after the September 11, 2001, terrorist attacks on the World Trade Center. Still wanting to help, the Wall Street community created a restaurant and wine-tasting event called Hope for the Children. The first time in a pioneer study of pediatric brain tumor patients. The study should enable doctors to plan radiation therapy so as to spare normal brain areas that could be affected by radiation. The research, presented at the December 2001 Annals of Neurology, was led by Grant Steen, PhD, of St. Jude Diagnostic Imaging.

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One chilly day last December, Sharon Atwell stood, transfixed, watching her youngest daughter carry the Olympic torch through the streets of Memphis. Amid a deafening tumult of cheers, shouts, sirens and applause, 15-year-old Katelyn Atwell waved serenely at the crowd and, with a radiant smile, quietly passed the Olympic flame to her mother.

Only two years earlier, Katelyn’s own flame had almost been extinguished by a bacterial infection that had catapulted her into the yawning void of a coma. Her journey back to the light has been slow, tortuous, and—in the words of many St. Jude researchers and health care providers—miraculous.

The candle flickers

Long before she ever held an Olympic torch, Katelyn Atwell had acquired the discipline and tenacious spirit of an athlete. A competitive swimmer, she spent countless hours in the pool, testing her limits. That same sense of determination also pervaded other aspects of Katelyn’s life. When her family moved from Florida to Tennessee, the outgoing youngster joined the band and the flag squad at her new school, and helped lead a children’s choir at church. Life was good; life was busy. Then her back began to hurt, and Katelyn went to the doctor. Soon the diagnosis came back: acute lymphoblastic leukemia.

In June of 1999, Katelyn began treatment at St. Jude...
Katelyn’s mother never left her side, constantly optimistic and determined, clinging to her faith in the midst of staggering odds. “I think Katelyn’s faith motivated her to live,” observes Robert Tamburro, MD. “A lot of times, people are unrealistic or irreligious, and act upbeat because they haven’t really accepted how serious the situation is. That was never the case with Katelyn’s family. They said, ‘We’re going to stick with our faith and be as upbeat and positive for Katelyn as we can, because that’s what’s she’s going to need.’”

Sharon watched as scientists and clinicians joined forces to fight for Katelyn’s life. “The people at this hospital don’t accept defeat gracefully,” Sharon says. “When you present them with challenges, they really go to battle. It was a hospital-wide effort. Our doctors would be beeped by scientists in the Danny Thomas Research Tower, who would say, ‘I’ve been researching Katelyn’s situation. Have you tried this or that?’ Every department was doing everything they possibly could—researching and calling other hospitals to see if they could find anyone who had ever had this infection before.”

At one point, a prominent neurosurgeon arrived to provide a second opinion on Katelyn’s condition. “He looked at the diagnosis, he saw the type of infection that she had, he looked at the CAT scan, and he told me, ‘You might as well kiss this baby goodbye and call your family in, because there is no hope for her,’” Sharon recalls. “I believe with all my heart that if she had been in any other hospital than St. Jude, they would have taken his word for it, and Katelyn would have passed away. But the folks at St. Jude said, ‘You know, we’re not ready to believe that yet, and they called in someone else.’”

Because of increased pressure within her brain, Katelyn underwent dozens of operations to insert drains, shunts and remove cysts. The trauma to her brain prompted what doctors called autonomic storms. Her temperature would plateau at 108 or 109 degrees for more than 12 hours. Her heart rate would skyrocket, and her blood pressure would increase to 200/185. The storms would abate for a couple of hours, and then they would resume with increased frequency. “We didn’t think she was going to make it,” says ICU nurse Peggy Derringer. “And we thought that if she did make it, the damage to her brain would be so profound that her quality of life would be terrible.” But Katelyn did not die. She remained in a coma for more than a year.

**Fanning the flame**

During that year, Sharon and Ray Atwell and their older daughter, Crystal, prayed relentlessly and celebrated each achievement, no matter how small. They leaned on their faith, friends and family for support. Through the Internet, people around the world heard about Katelyn and began to pray for her. Sharon sent out regular “Kate Update” e-mails to an ever-increasing number of “prayer warriors.” A huge map on the wall of Katelyn’s room marked the cities and towns where people were praying for her. “The idea to call Katelyn to know when she woke up how many people had prayed for her to be well,” explains Sharon.

The medical staff taking care of Katelyn were astonished by her family’s unwavering optimism and faith. “There was always a family member at Katelyn’s bedside, encouraging her, playing her favorite music, doing passive range of motion exercises,” recalls Stephen Thompson, MD. Katelyn’s caregivers received support, as well. “Whenever I’d operate on Katelyn, I’d get e-mails literally from all over the country—people saying, ‘We’re praying for you; we’re praying for Katelyn,’” recalls Stephanie Einhaus, MD. “It was incredible.”

Sharon compares Katelyn’s battle with Bacillus cereus meningitis to a roller coaster ride. As soon as doctors would rectify one problem, another would arise. She would begin to rally and then she would have a stroke. Or she would get a viral infection. Or she would have a seizure. But a year into Katelyn’s coma, her condition began to improve. Although she was blind and non-verbal, she began to respond to her family with hand squeezes, blinks or nods.

In a June 2000 “Kate Update,” Sharon wrote, “It was one year today that the Atwell family got on this roller coaster ride called the cancer express. It has more corkscrew turns, downward spirals, upside down turns, only to be shot straight up into the heavens or to find yourself plummeting down into the bowels of the earth. For a very long time I prayed every day for God to get us to the exit ramp, but we never did see it…We are now on a very smooth ride, every once in a while a whoop-tee-doo, but for the most part just an enjoyable, slow ride going forward.”

**In St. Jude Rehabilitation Services, Katelyn and Physical Therapist Assistant Janet Adams urge physical therapy students Raquel Bengoechea and Jenny Puff to bend ever lower in a high-energy game of ‘limbo.’**
sive medical care, made the difference. “She’s one of our true, bonafide, no-way-she-should-be-here miracles. And that’s the truth,” Derringer says.

As Katelyn began to surface, she quickly regained her competitive spirit and sense of humor. The rehabilitation specialists who had worked tirelessly with Katelyn during her coma now began to help her relearn the most basic tasks. With the daily help of physical, occupational and speech therapists, she began to make progress. She began to sit alone, then talk, then stand. In September, she had her last dose of chemotherapy. Two months later, she walked with her walker from Rehabilitation Services to the St. Jude reception desk, as St. Jude staff and patients lined the corridors and filled the lobby, cheering.

On Friday, December 14, Katelyn carried a flaming torch through the streets of Memphis. “I stood at the corner of the street, watching this huge entourage of people coming my way,” wrote Sharon in a “Kate Update.” “I stood there praising God for how great he truly is. Who would have ever thought two years ago that she would be coming toward her mother with torch in hand, waving at everyone with the biggest smile possible on her face? A vision of her in ICU with all the tubes and machines popped into my head, and then I looked at her coming toward me, and I almost lost it.”

Katelyn seems unaware that she has become a symbol of hope and faith to others. “Every time I see Katie, my heart just swells,” says Derringer. “Doctors, nurses, respiratory therapists, we all light up when we see Katie. When she walks into the ICU, we look up and say, ‘Ah! We’re so glad you’re here!’ She gives us inspiration, and she lifts our spirits.”

Let your light shine

During the past year, a silent girl with a blank stare has evolved into a vivacious teenager who greets everyone she meets with a broad smile and enthusiastic greeting. At any moment, Katelyn might break into a praise song, a joke or a pithy commentary. “There’s me as a body-woddy,” says Katelyn, as she marvels at the emaciated stranger depicted in her mother’s photo album. “I don’t remember diddly squat. All I remember is loud, annoying beeps.”

Katelyn doesn’t mourn about the time she has lost; she is too busy setting, meeting and exceeding goals. Today she is dressed for physical therapy in a navy sweatshirt, Florida Gators sweatpants and blue glitter nail polish. Sunlight streams through the windows of Rehabilitation Services, falling in a bright strip across the linoleum floor. For Katelyn, walking is still hard work, a task that demands intense concentration. Brow furrowed, head bowed, muscles quivering, she takes one step, a deep breath, then another.

“C’mon, girly girl! You can do it!” urges Sharon. Panting, Katelyn steps into the light, moving forward, ever forward. Instilled with determination, upheld by faith and propelled by the sheer power of a mother’s love.

According to a member of the committee that chose the Olympic torchbearers, Katelyn received hundreds oftorchbearer nominations—more than anyone else in the state of Tennessee. Although she originally intended to walk part of the route, Katelyn changed her plans to accommodate Olympic officials, who wanted the torch to move quickly.

The patients of St. Jude Children’s Research Hospital benefit enormously from what we know today as the Human Genome Project. Much of the hospital’s research has been accelerated by the project and its tools, found in the St. Jude Hartwell Center for Bioinformatics and Biotechnology. But what is this nebulous and official-sounding project and how does it help fight disease?
Forks, knives and genes

To understand the implications of the Human Genome Project, you must first understand the term “genome.” The On-Line Medical Dictionary defines a genome as “the total set of genes carried by an individual or cells.” Notice that the word “set” is used in this definition. A “set” also pertains to your mother’s silverware and place settings. If you stretch your imagination (not to mention a few laws of physics), you can draw some simple comparisons between our bodies and a dinner party.

Consider a table setting for about 1,000 people. Lots of china patterns, plus similar—but not quite matching—plates, saucers, coffee cups and many, many tables. A special name card adorns each place setting. Sounds complicated, but step back and it’s really grand and beautiful.

Each individual consists of millions of different cells (table settings), but there’s also a good bit of order to them. Assume that the Human Genome Project, which genetic researchers put in motion about a decade ago, is a gigantic place setting. Sounds complicated, but step back and it’s really grand and beautiful.

Researchers are trying to understand how genes function and interact. “Some diseases are associated with single-gene defects; others are involved with multiple genes,” Mirro explains. “With the Human Genome Project, you can go in and screen for diseases we’ve identified as single-gene defects, but someday we’ll be able to screen for diseases caused by multiple genes.”

“Can we better define the molecular abnormalities that cause cancer?” asks St. Jude Pathology Chair James Downing, MD. “Can we understand how these lesions lead to cancer? Can we use that information to develop better therapies that are more effective against cancer, yet less toxic?”

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The main course

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Forks, knives and genes

The Patient and the Project

DAVID Scanlan is one of the few St. Jude patients who understands exactly why the Human Genome Project is important. “I use tools, same as those used by the Human Genome Project, to break down DNA, read it and then put it back together,” says Scanlan, who was treated for non-Hodgkin lymphoma at St. Jude in the 1980s.

Scanlan, 26, spends his days “ripping apart” bacteria for The Institute for Genomic Research (TIGR), which collaborates with the National Institutes of Health and many companies to sequence genomes. “The microarray technology I use at TIGR, which is the same as that used in the Hartwell Center, helps us determine what genes are being turned on to make proteins that are expressed by individual cells,” he says. “We are studying bacteria that are closely related to the infamous anthrax bacteria. By examining the growth cycle, we hope to learn more about what genes are turned on in response to a variety of growth conditions.”

After completing cancer treatment, Scanlan couldn’t stay away from St. Jude—returning to work for a summer in the Immunology department with Nobel Prize-winner Peter Doherty, PhD. “I’ve always been interested in biology and medicine,” Scanlan admits. Today, the Virginia Tech graduate and proud cancer survivor lives in Washington, DC, as he makes plans to attend medical school.
Cost of treating a child with cancer per day: $2,220.
Cost of running the hospital per year: $270,464,436.
Cost of upholding the highest standards of medical excellence while saving the lives of the world’s children: Priceless.

St. Jude Children’s Research Hospital celebrates its 40th anniversary this year, and like a fine cabernet, the institution proves that some things really do get better with age. At 40, St. Jude has never looked better—sporting an unprecedented $1 billion expansion and world-renowned research. The past four decades have brought higher survival rates for every type of childhood cancer and new scientific discoveries and technology for more effective treatments. The hospital has come a long way from the one-building institution that set out with the ambitious idea of curing the sickest children without charging them. This success is possible because of the efforts of ALSAC, St. Jude’s fund-raising arm, and the hospital’s backbone: its volunteers, donors and employees.

Hospital founder Danny Thomas knew that well. At the dedication ceremony February 4, 1962, Thomas told the crowd of staff and supporters from around the country, “A dream is one thing. A realization is something entirely separate. I publicly thank you, wherever you may be, for the support of this dream. It took a rabble-rousing, hook-nosed comedian to get your attention, but it took your hearts, loving minds and generous souls to make it come true. If I were to die this minute, I would know why I was born.”

Adopting the mission

Danny Thomas was not the only person to find purpose at St. Jude. Thousands of employees have since taken on the hospital’s mission as a personal goal, whether through direct patient care, research or support.

Bobbie Fisher, a St. Jude Laboratory Services employee since 1964, has witnessed four decades of progress. “When I first came to work here, you could say that children were doomed,” she recalls. “I’m glad to say that I have lived to see that today our children are living; they are going to college; they’re getting married; they’re having families.” Back in the ‘60s, Fisher worked for 91 cents an hour, three days a week. Her belief in the hospital’s mission was so strong that after her shift ended at 5 p.m., she continued working in the labs until midnight for free. It was a service she called her “dedication time.” “And it wasn’t just me,” she says. “All of the people who have come to work for St. Jude have had the highest dedication and love and honor.”
Defining progress

Inventiveness is another word that can be added to that list. Time and again employees found ways to keep patient care at the highest level without wasting donor money. In the early years, ALSAC volunteers stretched donor dollars by using the backs of incoming mail and envelopes to make carbon copies of letters. The Ladies of St. Jude also re-rolled adding machine tapes in Accounting each evening so that both sides of the paper were used. Commercial blood banks used to pay blood donors $3 per donation; the banks then sold that blood to local hospitals for $25. That price seemed unreasonable, so St. Jude created its own Blood Donor Center. The hospital still draws most of its blood supply from this source.

A shrine to life

When St. Jude opened, leukemia was an incurable disease. Pat Patchell, 49, the hospital’s longest living acute lymphoblastic leukemia survivor, helped St. Jude change that. Patchell arrived at St. Jude in 1964 and responded quickly to treatment. He was one of the first five patients to be taken off medication after a long-term remission at a time when cancer patients received treatment indefinitely. “That was a brave, new idea at the time,” Patchell says. “I’m just so glad they had the nerve to do it. It gave me a lot of freedom.” Now a Memphis accountant, Patchell says he gets tongue-tied when discussing his feelings about St. Jude. “How can you express enough thanks, when you were in dire straits and they saved you? It really is the greatest place,” he says.

That sentiment would have pleased Danny Thomas, says Paul Parham, Thomas’ friend and retired director of ALSAC Communications. Thomas liked to discuss his feelings about St. Jude. “That was a pretty radical idea at a time when cancer patients either follow suit or forget about treatment. He was one of the first to make that vow, he was one of the first to do something different.” Parham recalls. “Every time I think I’ve done all that is possible, he gives me more to do,” Thomas would say.

Parham believes it is important for the world to remember Thomas. “Sure, he was a No. 1 TV star, but he was also this dynamic guy who would get things done,” Parham says. “It was his leadership, his dream, his goal and his fanaticism that built this place. He’d be very proud to see St. Jude today.”

The Giving “Family” Tree

longtime donor Judith Helmuth, of Farmington Hills, Michigan, was destined to become a supporter of St. Jude Children’s Research Hospital. Like the hospital, Judith was named after St. Jude Thaddeus, the patron saint of hopeless causes. Her family’s devotion to the saint has spread to support of the hospital, and now three generations of women are St. Jude donors.

It all started back in the 1940s during World War II when Helen Thomas’ parents were engaged. Her father was in the military and her mother, Dolores Nowicki, prayed to St. Jude Thaddeus not to send her fiancé overseas. Her prayers were answered, and her husband’s assignments were always on American soil. They never forgot the blessing. “My husband always said that we were going to name our first-born after St. Jude, no matter if it was a boy or a girl,” Nowicki recalls.

Nowicki’s devotion sparked her daughter’s fondness for St. Jude Children’s Research Hospital.

When she landed a job with Merrill Lynch, Helmuth decided to donate a portion of each paycheck to the hospital. She has done so for 17 years. “I think what St. Jude does for children and their parents by giving them the best care without asking them to pay is remarkable,” says Helmuth. She has never been to Memphis to visit the hospital, although she would like to someday. “I think of this as an act of faith,” she says. “I know the good work that goes on there, and that’s enough for me.”

Nowicki followed in her daughter’s footsteps in 1994 after having an operation for a perforated appendix. “It was a scary time in my life,” she says. “I just thought about St. Jude and decided that if I came through the surgery, I’d make a donation in his name.”

Now Helmuth’s daughter, Jessica Nienuis, 27, an industrial designer living in Chicago, carries on the tradition. She has made a donation to St. Jude as her mother’s Christmas present for the past two years. “It’s the best present I could ever think of,” says Helmuth. Jessica’s grandmother agrees. “I’m proud of her. You don’t see as many young people getting involved in these causes. I hope this encourages others. I can definitely tell them St. Jude really does work miracles.”

It’s pretty clear she was talking about both the hospital and the saint.
The tests that evaluate lung capacity and airflow provide entertainment and challenge to an inquisitive 10-year-old like Rodrick. “This is fun,” he says. “I like drawing pictures with my breath.”

“We want you boys to understand why we don’t want you to smoke,” says Melissa Hudson, MD. “Smoking can have long-lasting effects on the heart and the lungs. And it could give Rodrick a higher risk of getting another kind of cancer.”

Rodrick hops out of bed and dons clothes carefully chosen for this special day. He waits impatiently for the 7 a.m. arrival of the St. Jude shuttle. “I like going to St. Jude because when I was sick, I went there and they helped me out,” he explains. His mother, Ynetta Thompson, says he likes to go because “the nurses kiss on him.”

Rodrick was a toddler when he made his first trip to St. Jude. He had Hodgkin disease, a cancer rarely seen in children under the age of 5. After two years of treatment, his disease went into remission, and his checkups occurred every three months, then every six months, and then every year. Now the young cancer survivor is moving to the ACT Clinic, where he will receive care until he is 18 years old.

Deep in concentration, Ynetta fills out an ACT questionnaire that includes detailed information about Rodrick’s health status and family history. Meanwhile, Rodrick debates what he wants to be when he reaches adulthood. Should he be a police officer or firefighter?

Rodrick puts off the career decision when he hears his name called over the PA system. Dorothy Rogers in Echo/EKG is ready to test his heart function. When that activity is finished, Rodrick moves to another room where his lung capacity is evaluated. Next, he progresses to X-Ray, where he stands as still as a statue during lung X-rays. Hudson will use these and other test results to determine whether Rodrick’s past therapy is causing adverse effects and to predict problems that may arise.

A survivor of childhood cancer spends his first day in the St. Jude ACT Clinic.

Ten-year-old Rodrick Thompson of Memphis loves playing dodge ball, basketball and hide-and-go-seek. He loves eating pizza and reading books. And he loves coming to St. Jude Children’s Research Hospital for his yearly checkups.

For as long as he can remember, Rodrick has been a patient in the “A” Clinic at St. Jude, where he has received treatment and follow-up care for Hodgkin disease. But today he begins a new adventure, visiting the After Completion of Therapy (ACT) Clinic for the first time.

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For as long as he can remember, Rodrick has been a patient in the “A” Clinic at St. Jude, where he has received treatment and follow-up care for Hodgkin disease. But today he begins a new adventure, visiting the After Completion of Therapy (ACT) Clinic for the first time.

Rodrick hops out of bed and dons clothes carefully chosen for this special day. He waits impatiently for the 7 a.m. arrival of the St. Jude shuttle. “I like going to St. Jude because when I was sick, I went there and they helped me out,” he explains. His mother, Ynetta Thompson, says he likes to go because “the nurses kiss on him.”

Rodrick was a toddler when he made his first trip to St. Jude. He had Hodgkin disease, a cancer rarely seen in children under the age of 5. After two years of treatment, his disease went into remission, and his checkups occurred every three months, then every six months, and then every year. Now the young cancer survivor is moving to the ACT Clinic, where he will receive care until he is 18 years old.

Deep in concentration, Ynetta fills out an ACT questionnaire that includes detailed information about Rodrick’s health status and family history. Meanwhile, Rodrick debates what he wants to be when he reaches adulthood. Should he be a police officer or firefighter?

Rodrick puts off the career decision when he hears his name called over the PA system. Dorothy Rogers in Echo/EKG is ready to test his heart function. When that activity is finished, Rodrick moves to another room where his lung capacity is evaluated. Next, he progresses to X-Ray, where he stands as still as a statue during lung X-rays. Hudson will use these and other test results to determine whether Rodrick’s past therapy is causing adverse effects and to predict problems that may arise.

With the tests completed, Rodrick and his family go meet their ACT social worker, Sally Ward. “We’re happy to have you in the ACT Clinic. It’s a really good place to be because that means you’re a survivor of cancer,” says Ward, who will delve into Rodrick’s emotional, social, educational and financial concerns. She will also spend hours discussing community resources with him. “Before you graduate from the ACT Clinic, it’s important that you learn all the things you need to know to be a healthy survivor of cancer,” she says. Ward gently quizzes...
Rodrick about his lifestyle, emphasizing the importance of making healthy choices. Eventually, she will help him explore health insurance and access to medical care—two issues that often plague cancer survivors. “Do you think you want to go to college one day?” she asks. “Yes,” he replies. “Well, there are some scholarships for people who care cancer survivors, and we’ll be sure and talk about them,” she promises.

After the social work appointment, the Thompsons greet Margie Zacher, data coordinator for the St. Jude Longterm Follow-up Study. She offers Rodrick the opportunity to participate in the study. “We not only track your progress to give you good quality care, but we also use information from the study to continue our research into late effects,” she explains. Rodrick and his mother agree to participate and sign release forms. In addition to educating survivors and their community physicians, Hudson and her CCSS colleagues are acquiring new knowledge about the long-term effects of cancer and therapy. “I think it’s important for institutions to combine their expertise and their patient populations in research initiatives like this one,” says Hudson. “This study will give us a comprehensive look at what is happening to the survivors throughout the country.” Hudson also uses the forum to share St. Jude educational materials and programs with patients nationwide.

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If all goes as planned, Rodrick will graduate in 2010 from the ACT Clinic. The day he becomes an alumnus, he will receive a special book called a Personal Health Record. St. Jude is the first center in the United States to present these books to alumni.

Rodrick’s book will include treatment summaries, copies of medical reports, recommended timelines for tests and screenings, and healthcare guidelines specifically created for him. The document will give his physicians easy access to his medical information and to St. Jude. The book will also provide follow-up forms and phone numbers that Rodrick can use to keep in touch with St. Jude.

Armed with his ACT education, Rodrick will benefit from the support of St. Jude’s Children’s Research Hospital. He looks toward the hospital and thinks of the children there who are battling deadly diseases every day, and he sends a little hope and love their way with his thoughts.

He can’t see any of the children, of course. But he knows right where the hospital is supposed to be by heart. He can see it, even from 40,000 feet.

Captain Bernard “Bernie” Doubler is a pilot for Delta Airlines. Quite often when he takes the helm of a Boeing 757 or 767, his flight path guides him over Memphis, giving him a little bird’s-eye view of St. Jude. “Every time I fly over Memphis, it is a reminder to me of the children and what they are going through and all the wonderful work the incredible people at the hospital are doing,” he says.

A native Tennessean, Doubler knows the children of St. Jude. He thought he could visit with them and tell them about his job as a pilot, tell them how airplanes work, and—if only for a little while—make them forget that they were sick.

His presentation has evolved over the years and now includes video of the movie The Spirit of St. Louis, the story of Charles Lindbergh’s flight across the Atlantic. He relates Lindbergh’s dangerous—yet triumphant—journey to each of the patients’ lives. “When Lindbergh made his epic flight … he overcame many obstacles along the way and many dangers,” Doubler says. He tells the children that he knows they are fighting long and difficult battles, “but if they can just be like Lindbergh and take it an hour at a time and a battle at a time, hopefully they can win the war.”

Doubler enjoys being with the children and misses them when he is away. That’s why he always looks in on St. Jude whenever he passes through the Memphis sky. He could be watching right now.
Mickey Heffernan used to have a skeleton in the closet. As a result of participating in a bone density research project at St. Jude Children’s Research Hospital, he now has one on the wall, as well.

A survivor of acute lymphoblastic leukemia (ALL), Heffernan knew that cigarette smoking could harm his lungs and heart and put him at risk for other kinds of cancer. But when he enrolled in a protocol studying bone mineral density, Heffernan learned that his nicotine addiction was literally leeching the calcium out of his bones. In response, Heffernan created an award-winning oil painting titled “My Habitual Hypocrisy” and redoubled his efforts to quit smoking. “My little skeleton in the closet was my smoking,” admits Heffernan, who is studying art at the University of Arkansas, Fayetteville. “This painting was about my addiction to cigarettes and how it was pretty stupid.”

When Sue Kaste, DO (Doctor of Osteopathy), of the St. Jude Diagnostic Imaging department began studying the bone density of childhood ALL survivors, she never dreamed that her research might inspire a work of art. She did hope that it would improve the quality of life for cancer survivors. Several years ago, the pediatric radiologist noticed that the bones of many St. Jude patients looked “washed out” on X-rays. “I wondered if my eyes were failing me or if, in fact, our kids had bone mineral deficits,” Kaste recalls. Lower bone density might signal the early onset of osteoporosis, a silent bone disease that is not usually detected until late adulthood. People who suffer from osteoporosis have weak, thin bones that can break easily. Depending on the extent of bone loss, osteoporosis may be accompanied by severe pain, deformity, fractures and loss of height.

Bones at risk

In conjunction with endocrinologists and researchers from Hematology-Oncology and Biostatistics, Kaste studied 141 survivors of childhood ALL who had been off therapy for at least four years. Sure enough, the team found that the participants were at increased risk for developing osteoporosis. Sixty-eight percent of the patients had a bone mineral density below normal, and 14 percent of those survivors fit the criteria for osteoporosis.

Most people assume that osteoporosis is a disease of older women. But men are at risk, too. “My own dad actually suffers from adult onset osteoporosis,” says Kaste. Using a process called quantitative computed tomography (QCT), the St. Jude researchers found that boys actually experienced more bone loss than girls. In the past, patients received cranial and spinal radiation as a standard part of ALL treatment. The researchers discovered that children who had received these high doses of radiation had lower bone density, as did Caucasians and patients who had undergone intensive chemotherapy.

Kaste found that the ALL survivors were just like their peers across the nation: most of them had undergone intensive chemotherapy. The overall diet of the average adolescent has really gone down the tubes in the last couple of decades, and it’s reflected in the St. Jude population,“ observes Kaste. About 70 percent of American teen-agers do not get the minimum daily requirement of calcium. And few teens realize that cigarettes, caffeine, sodas and alcoholic beverages are bad news for bones. Also, a patient undergoing therapy may not feel like exercising—another risk factor for osteoporosis. “When you take the normal adolescent lifestyle and then you compound it with the effects of disease and treatment, you see kids who are actually getting older bones at a young age,” says Kaste.

Bone boosters

When St. Jude opened its doors 40 years ago, only 4 percent of patients survived treatment for ALL, the most common form of childhood cancer. Today, with the survival rate at 80 percent, thousands of ALL patients are reach-
ing adulthood. “Now that we’ve been so successful with cures, we have to work on reducing the adverse effects of those cures,” says Kaste. “It’s sort of a double-edged sword. We’re blessed with a large survivor cohort, but we’re also plagued with some of the complications, and now we have to tackle those, too.”

Armed with information they have learned about bone mineral loss in St. Jude survivors, Kaste and her colleagues are now looking at ways to solve the problem. Their current study will include about 335 ALL survivors. In addition to identifying other risk factors, the researchers are studying the role of genetics in bone mineral loss. They are using two methods of testing bone loss in these patients—QCT and dual x-ray absorptiometry (DEXA). The researchers are trying to find a way to reduce the loss of bone mineral in survivors, and to prevent that loss in future patients.

To test the effectiveness of dietary supplements, half of the study’s participants are taking calcium and vitamin D; all of the adolescents are receiving intensive nutritional counseling as part of the three-year project.

St. Jude researchers are also studying osteonecrosis, which is sometimes called “bone death” or “avascular necrosis.” “Osteonecrosis is usually an adult process,” explains Kaste. “Kids don’t get it. Except for our kids—young patients who have had radiation therapy or certain medications such as steroids.” Kaste says clinical care at St. Jude has been revamped so that clinicians are constantly looking for symptoms and risk factors associated with osteoporosis and osteonecrosis, and they are ready to spring into action if they suspect that a patient is losing bone mineral.

“There are some modifications of therapy that can be done,” says Kaste, “We don’t want to sacrifice cure, but we want to minimize the adverse late effects.”

**Healthy living for life**

Nick Lawrence from Louisiana is one of those survivors who found out he was a 20-year-old with “old-age bones.” He says he has changed his eating and exercise habits as a result of participating in the interventional study. “Now I eat a lot of cheese, cereal and ice cream,” says Lawrence, “and I play basketball, do pushups and lift weights.” Lawrence’s calcium levels have increased after being on the study for a year.

Unlike most of her friends, 18-year-old Lindsay Rosales has always enjoyed calcium-rich foods and strenuous exercise on a regular basis. As part of her frenetic schedule, the high school senior from Illinois runs, does pull-ups and push-ups at a local camp for cancer patients and serves as captain of her school’s cheerleading squad. But in spite of her healthy lifestyle, Rosales’ bone density levels were low as a result of the ALL treatment she completed in 1993. Her mother, Sue Ellen Patkunas, is thankful that Rosales was targeted for the research project. “They say that bones continue storing calcium through your 20s and 30s, so there’s still time to do something for Lindsay,” Patkunas says. “I’m glad they found this out, and that they’re able to do this study.”

Heffernan, a college freshman, says involvement in the osteoporosis protocol has transformed the way he eats. “I used to drink a lot of carbonated beverages, but I don’t anymore. It’s solely because of the study. Now I drink more milk, water and different kinds of juices, and I eat cereal in the mornings. Today, I came home from class and said, ‘Oh, what to eat?’ and I thought, ‘Oh, I’ll have a grilled cheese sandwich!’ So it’s influenced me a lot. Before, I never really paid attention to what I ate. Now, I have to pay attention.”

**Tomorrow’s survivors**

Kaste and her colleagues are following about 2,000 survivors as part of their bone density studies. Juggling that much data is an enormous undertaking, but one that may yield life-changing results for survivors of childhood cancer.

Information gleaned from the studies will eventually be used to help other St. Jude patients, such as children with solid tumors, bone marrow transplants and HIV/AIDS. “It’s a tremendous opportunity,” says Kaste. “Seeing the impact that we’ve made in just a little over four years is very rewarding, but very humbling at the same time. We’ve got a lot of work to do, and we are just chipping away at it.”

In the meantime, former patients like Nick Lawrence, Mickey Heffernan and Lindsay Rosales are doing all they can to help in the research—taking supplements, filling out nutritional questionnaires, and, in Heffernan’s case, creating artwork that wins awards and sparks discourse. “One of the reasons I’m doing this study is because I feel like I’m giving back,” says Heffernan, who began painting at the age of 4, when he was in treatment at St. Jude. “The people at St. Jude gave me so much. They saved my life. So if studies like this come up, I should do them. It’s my small way of giving back.”

Karen Smith, research and education coordinator in Clinical Nutrition, meets with Nick Lawrence of Louisiana as part of the bone density study. During the session, they discuss tactics for increasing calcium and vitamin D in the diet.
Several years ago when I was asked to join the Professional Advisory Board at St. Jude Children’s Research Hospital, I was delighted and honored.

I knew that some wondrous things were happening at St. Jude, but only after joining the board did I begin to realize and appreciate the scope of research and treatment taking place there. The best and the brightest populate the research labs, with programs in place to find treatments for sickle cell anemia, AIDS, leukemia, cancer and a myriad of childhood diseases that I don’t even know the names of.

Of all the words in the English language, few are scarier than the word cancer. I know from first-hand experience, because last year my doctor told me that I had prostate cancer and it just knocks the props out from under you as your mind floods with all kinds of horrible thoughts. Thank God I had successful surgery and am now cancer free. But I know the fear and worry that being told that you have cancer brings. I know what it did to me, and I’m a 65-year-old man. I can’t imagine what it must do to the mind of a tender child and their parents. I feel that one of these days somebody is going to look into a microscope and say, “There is the cure for cancer,” and it may well happen at St. Jude. And that’s not just a dream. I remember when polio was one of the most feared diseases known to mankind.

But polio had a lot of enemies. People like Jonas Salk who refused to give up, no matter how many times they failed, until that blessed day when they discovered the vaccine. Well cancer, leukemia and all catastrophic childhood diseases have a lot of enemies, too. And many of them work at St. Jude Children’s Research Hospital. They hate sickness and disease. They hate seeing children who can’t have a normal childhood because of illness. They hate it, and they are doing something about it. Of course, all of this costs a lot of money. When I think about the absolute fact that money, or lack of it, could be the difference between precious children living and dying, it makes me want to do everything I can to make sure the good people at St. Jude have everything they could possibly need to finish the job they’ve started.

One of my favorite stories, which happens to be true, is about a man who had a gold claim many years ago. He dug and dug and found no gold until he got discouraged and quit. One of his employees took over the claim and went back to work, only to discover a rich vein of gold one foot deeper than the former owner had dug.

My analogy is that it would be a world-class shame to stop a few million or billion dollars short of finding cures and treatments for suffering children. We don’t want to stop one foot short of the gold, or the goal in this case. I believe in St. Jude, I believe that the motivation is pure and the love is real, and I will gladly be a part of anything I can to see that the great work continues.

With my prayers, my support and my love,
Charlie Daniels

A valued member of the St. Jude Professional Advisory Board, Grammy award-winner, author and actor Charlie Daniels is internationally renowned for his work in country, rock and gospel music. In addition to selling more than 13 million albums, he has garnered countless hits, platinum recordings and has published a book of short stories.

Talk about leaving your stamp on society. Australia has honored St. Jude immunologist Peter Doherty, PhD, by placing his image on a postage stamp. Doherty, who has worked at St. Jude since 1988, won the Nobel Prize for Medicine in 1996, an honor he shared with Rolf Zinkernagel of Zurich, Switzerland. The two laureates discovered how T-lymphocytes of the immune system recognize virus-infected cells. The stamp featuring Doherty is part of the “Australian Legends” series of postage stamps. In the past, Australian Legends series have included Olympic medalists, musicians, soldiers and artists. The 2002 series honors “five Australian scientists who changed the world.”

A Place for Healing

“Using your words, my support and my love,” By Charlie Daniels

find treatments for sickle cell anemia, AIDS, leukemia, cancer and a myriad of childhood diseases that I don’t even know the names of. 

Of all the words in the English language, few are scarier than the word cancer. I know from first-hand experience, because last year my doctor told me that I had prostate cancer and it just knocks the props out from under you as your mind floods with all kinds of