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

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

Promise is a quarterly publication of the Department of Public Relations of St. Jude Children’s Research Hospital. It is devoted to finding cures for children with catastrophic diseases through research and treatment.

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From nose to yes

Children with cancer who are especially susceptible to influenza infection because chemotherapy has weakened their immune systems might benefit from a vaccine (LAIV) that could protect humans against a bird flu virus. It is administered via nose drops. The researchers reported that the vaccine’s ability to protect against both human flu viruses and H5N1—the bird flu virus—suggests that it could protect humans if an H5N1 virus mutates so that it can pass easily from person to person or become endemic in a laboratory model. The investigators found that the virus could be transmitted from one cell to another within a few days, which could speed development of novel drugs to treat the disease.
Three Times Is a Charm

By Ruth Ann Hensley

PHOTOS BY ANN-MARGARET HEDGES

It was an autumn afternoon in a suburban Illinois supermarket, and 5-year-old Sierra Josephsen was down to her last dollar. Some might say she had fallen on hard times, and in many ways they would have been right. But Sierra’s concerns went much deeper than mere finances. That day, the vibrant girl sporting a bob of golden hair and shimmering hazel eyes was consumed with only one thought—to win; to beat the odds of the game she was playing.

While her mother scanned the aisles for groceries, Sierra tentatively put her last bill in the crane machine. With a firm grip on the handle, she slowly lowered the metal jaws to clench a prize from the stack of stuffed animals filling the glass box. Passersby paid the girl little notice. They couldn’t possibly know that Sierra had recently received her third cancer diagnosis... that a doctor had told her parents, “You will be burying your child” and that a doctor had told her parents, “You will be burying your child” and that the family was anxiously awaiting a phone call from a hospital that offered their last hope.

Suddenly, Sierra felt a tug at the end of the chain. With a resounding thud, the crane released its treasure into the collection bin. “I won!” she breathlessly exclaimed, clinging to a small doll wearing a “Miracles Happen” T-shirt.

It was the first sign that perhaps Sierra could beat the odds in a game that really mattered, where the stakes were life and death.

Survivor

“We come to St. Jude with that doll every time,” Sierra’s mom, Sandy, says, “because miracles do happen.”

Ed and Sandy Josephsen witnessed a miracle the day Sierra and her identical twin sister, Savana, were born. “I was so happy that they were healthy,” Sandy says. The girls pursued the inquisitive, playful and boisterous activities that all toddlers enjoy, but when they turned ½ years old, Sandy noticed some disturbing changes in Sierra. “She would cough until she turned white,” Sandy recalls, “and her tummy started getting bigger.”

Sierra’s pediatrician concluded that she had asthma and prescribed daily breathing treatments. After numerous breathing treatments, Sierra’s stomach was still distended. “Finally,” Sandy recalls, “I said to Sierra’s doctor, ‘Her tummy does not look like Savana’s at all.’” The doctor intently pressed on Sierra’s abdomen, and the color drained from his face. “Let’s go down the hall for a chest X-ray and an ultrasound—and call your husband,” he said.

Sandy called her sister first because she lived nearby. “Sue, you’d better get over here. I think they’re going to tell me that Sierra has pneumonia,” Sandy said. Moments later, the family learned that Sierra had cancer. “I had to leave the room,” Sandy says. “I couldn’t breathe.”

Sierra was found to have Wilms tumor, also known as nephroblastoma. The fourth most common type of cancer in children, Wilms tumor arises from the disordered development of embryonic kidney cells—immature cells that normally regress by birth but can become cancerous if they persist into childhood. Two days later, surgeons removed a 16-centimeter tumor and Sierra’s right kidney. It was a frightening blur of activity for the Josephsen family, but after the successful surgery they could breathe again. “Sierra was a stage II, which meant there was a 90 percent chance she would never have cancer again,” Sandy says, “and they told us they got the whole thing.”

Sierra won her personal version of Survivor and a wish to go to Walt Disney World®. No one imagined that during a regular check-up, 14 months later, doctors would announce that her cancer had returned.

“I felt like I was shot in my chair,” says Sandy, who remembers every moment of that day with Rain Man-like adeptness. “It was September 11, 2002,” Sandy says. “Bad date.”

Sierra’s cancer had returned in exactly the same place as before, but the tumor was large and the prognosis was not good. After high-dose chemotherapy reduced the mass to the size of a tennis ball, surgeons removed it.

“They said they got the whole thing,” Sandy recalls. “We followed up the surgery with a double stem cell trans-
After enduring a recurrence of cancer, five bowel obstructions and her third major surgery, Sierra won round two of a deadly competition and a wish for a dog—a black Labrador retriever named Survivor.

“I know it’s bad when the oncologist is crying with you,” Sandy says.

Wilms tumor, which has an 85 percent survival rate, proved a wily adversary for Sierra, but she was about to enlist a powerful ally.

“I told the oncologist, ‘We can’t stay here any more; you’re not giving us any hope,’” Sandy says. “When the doctor asked where we would go, I said, ‘Anywhere—anywhere that gives us hope.’”

Sierra’s pediatrician conducted a frantic search and discovered that St. Jude Children’s Research Hospital had just begun a trial for Wilms tumor patients using the drug topotecan.

“It was a godsend that they were running the trial at the same time for the same type of cancer that Sierra had,” Sandy says, reliving the joy of that discovery. “It was another sign.”

Laboratory studies directed by Jeffrey Dome, MD, of Hematology-Oncology and Peter Houghton, PhD, of Molecular Pharmacology showed that topotecan was an effective drug in the treatment of Wilms tumor. “We also had encouraging data from patients treated on Phase I studies of topotecan, conducted at St. Jude,” Dome says. “The combination of the laboratory data and early clinical data strengthened the light bulb to start a clinical trial of topotecan specifically for patients with Wilms tumor.”

Once team members determine the medication’s most effective administration schedule, they adjust or individualize the topotecan dosage as part of a treatment regimen called pharmacokinetic targeting. “It’s beautiful in a way because we measure the topotecan levels in the blood, and it’s variable from person to person; so if the dose is too low we increase it and vice versa,” Dome says. “There are very few chemotherapy drugs where we can do that, so it’s a tremendous benefit.”

Dome says the promising results of this study, due to St. Jude, have prompted the Children’s Oncology Group and the International Society of Pediatric Oncology to consider a proposal using topotecan as the standard chemotherapeutic for recurrent Wilms tumor.

Hope

As a result of this treatment, 8-year-old Sierra has been cancer free for nearly two years. “Being a three-time survivor of Wilms tumor is extremely rare because survival rates diminish with each recurrence,” Dome says. “The further out she gets, the better off she is.”

“Sierra says she gets her strength from her sister, Savana, who beat down her fierce competitor for the third time. Dome says the family doctor named one of her dogs Topotecan, after the drug used to eradicate her tumor. She gave a photo of the canine to Clinton Stewart, Pharo, of Pharmaceutical Sciences, who contributed to the Wilms tumor protocol. “When people tour our lab, I tell them how much things cost,” Stewart says. “One instrument is $80,000; one is $400,000. But then I tell visitors, ‘This is what makes it all worthwhile; this is priceless’—and I pull out a picture of Topotecan.”

A Hole-in-One

For more than four decades, the FedEx St. Jude Classic has grown and evolved, raising more than $16.5 million for the hospital.

I can never say how thankful I am to Dr. Dome, the PK [pharmacokinetic] nurses and everyone who has helped us on our journey here,” Sandy Josephson says. “How do you repay a hospital for saving your child’s life?”

“The combination of the laboratory data and early clinical data strengthened the light bulb to start a clinical trial of topotecan specifically for patients with Wilms tumor.”

“One instrument is $80,000; one is $400,000. But then I tell visitors, ‘This is what makes it all worthwhile; this is priceless’—and I pull out a picture of Topotecan.”

By TIFFANY STRANGE
A ny seasoned soldier knows the tactical value of having the right ammunition and a well-defined target. At St. Jude Children’s Research Hospital, researchers and clinicians are wielding a formidable weapon called molecular-targeted therapy. This assault on pediatric cancer requires that they pinpoint specific targets, acquire the best ammunition and take aim to ensure direct hits.

One scientist on the front line of this war is Richard Gilbertson, MD, PhD, of St. Jude Developmental Neurobiology and Hematology-Oncology. As he templates his battle plan, Gilbertson frequently mentions how treatments have changed since the “olden days,” a scant 10 years ago, when clinicians used the same therapy to treat every child suffering from a specific type of cancer. But as St. Jude scientists learn more about the human genome and specific genetic mutations, they are finding new strategies to ambush the enemy—childhood cancer.

On target

When using molecular-targeted therapy, researchers’ first task is to identify the target and find patients who have it. Most anti-cancer drugs are designed to combat genetic mutations that make cells malignant. To qualify for a clinical trial based on molecular-targeted therapy, a patient cannot simply have the specific disease under study; the child must also have the specific genetic target.

“If you don’t have kids with that target in your study, then there is a great chance that they won’t respond to that drug,” Gilbertson says. “For instance, if you try a drug in patients and only a few or none of them respond, then your conclusion used to be that the drug was rubbish; it didn’t work. But that’s not necessarily the case. Perhaps it didn’t work because you didn’t put it into the right patients.”

So how do scientists identify the right patients? One option is to sequence the whole genome to look for mutations. The process is costly, laborious and time consuming. Sequencing just one gene can take a week to complete. But Gilbertson and his colleagues have discovered a quicker and less expensive way to identify children with specific targets. Using technology available in St. Jude’s Hartwell Center for Bioinformatics and Biotechnology, the researchers generated gene expression profiles of medulloblastoma tumor samples.

Gene expression profiling is a method of determining which genes are active in certain cells. The St. Jude team used a technique that looks at the expression of 18,000 genes at once in a tumor. Based on these studies, the scientists identified signatures related to the kinds of genes that were expressed. These signatures accurately predicted the presence of mutations. The researchers also discovered five distinct medulloblastoma subgroups.

“No, if a kid walks in the door, we can complete a single test that takes half a day to do,” Gilbertson says. “We will be able to say, ‘You’ve got a mutation of this gene, and you should go into this clinical trial.’”

“What we understood 10 years ago to be medulloblastoma or ependymoma are probably four or five different diseases that just happen to look the same through the microscope. It’s actually a pretty innovative venture,” says Gilbertson, the facility’s director.

To accelerate progress in this area, St. Jude has created the Molecular Clinical Trials Core, a central reference laboratory that helps scientists plan and execute clinical trials of molecular-targeted therapies. The facility provides its users with advice, support and molecular analyses. “It’s actually a pretty innovative venture,” says Gilbertson, the facility’s director.

The core is currently handling 10 molecular-targeted clinical trials encompassing several signaling pathways and tumor types. Samples from St. Jude and across the United States are sent to the facility. Inga Warr and Radhika Thiruvenkatam, senior research technicians, process the material and perform the necessary assays. A recent clinical trial performed in the facility clearly indicated that the drug under study worked well in a population of more than 200 patients. The findings clearly indicated that the drug inhibited its target.

“In the olden days, you would give a drug to patients and just measure whether the tumor shrank or not,” Gilbertson says. “The assumption was that if it shrunk then the drug was good. That’s a no-brainer. But if the tumor didn’t shrink, the only conclusion was that the drug hadn’t worked. But you really need to know whether the drug got there and did its job. And unless you know that, you can’t fairly judge whether a drug is good or not.”

As they join forces and gain even more information about molecular-targeted therapy, St. Jude researchers and clinicians are determined to win the war against pediatric cancers. •
In an effort to understand—and halt—avian influenza, St. Jude scientists sequence 250 genomes and 2,800 individual genes.

Influenza has likely been in existence as long as human beings have walked the Earth. Even the ancient Greeks described its symptoms. Each year, some 20,000 to 30,000 Americans die from influenza, mostly the elderly and people with compromised immune systems. The most serious recorded influenza outbreak happened in 1918, when 20–100 million people died worldwide. Scientists fear that one strain, H5N1, spread by wild, migratory waterfowl. This is the first time in more than 70 years that this bird flu pandemic can be fought—unless you’ve been living in a cave for the past two years, you’ve heard about avian influenza, or “bird flu.” That’s the nickname for a class of influenza viruses that scientists call H5N1, from the subtypes of two proteins that give influenza its name: hemagglutinin and neuraminidase.

Scientists believe that the H5N1 virus, or the so-called bird flu, could mutate into a form that could transmit easily between humans. That possibility and the desperate need for knowledge about these elusive bird viruses sparked an enormous research project in the Hartwell Center for Bioinformatics and Biotechnology at St. Jude Children’s Research Hospital. Using sophisticated biotechnology instruments and a supercomputer, scientists mapped out DNA sequences inside hundreds of the viruses. Looking like enormous colored barcodes from a grocery store label, the bits and pieces of genetic information were laid out in their entirety for the first time. St. Jude researchers shared the data with the world in hopes that a deadly bird flu pandemic can be fought—or even stopped before it starts.

Why did the Hartwell Center tackle that project? “Simply because there is very little information about bird flu viruses, and these viruses constitute the source of all influenza viruses that are known to infect humans and animals on the planet,” says Clayton Naève, PhD, the center’s director. He and his staff plucked viruses from a collection gathered during a 30-year period by Robert Webster, PhD, a world-renowned avian influenza researcher who holds the hospital’s Rose Marie Thomas Chair in Infectious Diseases.

“It was important for us to get this information,” Naève says. “Having the DNA sequence of the complete genome of several hundred viruses gives us a tremendous amount of knowledge about these viruses—how they relate, how the genes in those viruses can re-assort and evolve, and which genes are important in the transmission from birds to humans or humans to humans.”

The amount of data the team gathered is astonishing. St. Jude scientists mapped out 70 million base pairs of raw sequence data—including 250 complete genomes. This process took so much computer power that, when a home PC tried to crunch the data, the machine would run nonstop, 24 hours a day, seven days a week, for nearly nine years.

Researchers found what Webster calls a gold mine of new information. They discovered new virus families that they didn’t know existed in the bird flu population. That is one of the factors contributing to the current high death rate in Asia and Europe. This is the first time since the 1918 pandemic that this bird flu virus protein has been introduced into human cells.”

Like a hitchhiker who turns violent and murders the driver who picked him up, the non-structural, or NS, protein in the avian virus has a component that, when introduced into human cells, binds to specific cell proteins and forces them to do as it commands. This process most likely leads to the death of the infected cell. St. Jude researchers believe this may explain why the death rate among people in Asia infected with H5N1 is nearly 50 percent—horribly high.

The Hartwell Center is designed to unlock the secrets and mysteries of killer viruses, proteins, genes and genomes at the most basic level. Twenty years ago, the center contained only one piece of equipment; now it has grown into a world-class facility with seven laboratories and a data center, which provides advanced biotechnology and bioinformatics support for St. Jude research.

These laboratories produce information about the most fundamental molecules in cells. The detailed, microscopic pieces of information are key to understanding many organisms. For example, DNA sequence information is helping St. Jude researchers understand why one patient’s cancer responds to a particular drug while another patient’s does not, and what may work instead. This information holds promise for St. Jude patients, avian influenza researchers, and scientists in general, and it is all due to the generosity of donations made to the hospital.

Naève and the Hartwell Center team constantly look to the future. “In the old days it took us a year and a half to collect 7,000 bases of DNA sequence,” Naève recalls. “Today we can produce 150,000 bases in four hours. We are hoping to deploy next-generation technology that can generate 20 million base pairs in five-and-a-half hours.”

“What we have clearly demonstrated here in the Hartwell Center is that an investment in technology pays off in new knowledge, new discoveries,” he concludes. “These are tools for discovery. And the more tools you have—the better tools you have—the more you are going to learn and the more progress you are going to make.”
John Alston was still reeling from the loss of his dad to Lou Gehrig disease when doctors discovered a football-sized tumor in his own chest. Like his father, who was a gifted vocalist, John is a musician who amazes audiences with his skill and harmonic depth. Today, the talented pianist has his sights set on a career in music.

The music that courses through a mother’s soul is beautiful and terrible. Quavering with a baby’s first cry, it rises to glorious crescendos, shimmers with passion and peace, exultation and loss. Beverly Alston has memorized every measure of this magnificent opus. As she watches her son’s strong hands dance across the keyboard, she marvels at just how precious that melody is.

When 18-year-old John Alston plays the piano, the room reverberates with emotion, evoking sorrow and solace, passion and peace, exultation and loss. Listeners may be surprised that a performer so young is capable of displaying such harmonic depth and maturity. But Beverly knows that her son’s musical gift is a complex composition of pain and joy that transcends mere technical ability.

As dedicated parents, Beverly and Bobby Alston led busy, fulfilling lives. A full-time firefighter, Bobby traveled the region as an accomplished gospel singer and served as associate pastor of a local church. As she home schooled their kids, Beverly constantly sought creative ways to weave Christian precepts and enrichment activities into a challenging academic curriculum. The Alston children flourished, their achievement tests indicating progress well above grade level. But Beverly’s chief consideration was not academic prowess. “Children can be A and B students but lack character,” she says. “As my children grew, I saw something in them that touched my heart—it was their love of people, their mannerisms, their concern, their attitudes.”

When Bobby began to have problems breathing, a doctor told Beverly that her husband was suffering from mini seizures. Then the muscle tremors began. After visiting several physicians, the family finally received the cruel news: Bobby had amyotrophic lateral sclerosis, or Lou Gehrig disease. A progressive condition affecting nerve cells in the brain and the spinal cord, the disorder paralyzes the muscles that control movement, speech, swallowing and breathing. Eventually the day arrived when Bobby required assistance to don his firefighter’s uniform. He had no choice but to retire.

Elegy and faith
In the meantime, John occasionally began to suffer from chest pain and insomnia. “It would just come and go,” he recalls. In April of 2005, Beverly made a medical appointment for him. “You tell the doctor that I said to run chest X-rays,” she instructed. But the physician did not
extend her stay when John found out he had cancer. "John's family is extremely supportive," says John, his mom and his sister Danielle pause for family time in front of Target House. Last year, around him.

Beverly sat in her car on the side of the road and wept, muffling her anguish with the rhythm. The hymn grows in intensity, culminating in a storm that engulfs his mother in wave upon wave of sound. Buffeted by this musical tempest, Beverly feels the depths of pain John has endured and contemplates the possibilities that lie ahead. She gazes at her only son... and smiles.

A couple of days after his dad's funeral, John said, "Mom, my chest is still bothering me." This time, Beverly accompanied her son to the doctor. When an X-ray indicated something unusual, the physician scheduled a CAT scan. After that test, Beverly was driving through the countryside when her cell phone rang. “John has a mass,” the doctor told her. “It’s pretty large. We’ll need to get a biopsy.”

A biopsy revealed that a football-sized tumor was growing in John's chest, obstructing his breathing and pressing on his heart. The physician called St. Jude Children's Research Hospital; the next day, Beverly and her son were in Memphis.

At St. Jude, the family learned that John's cancer was a mediastinal large B-cell lymphoma, a type of non-Hodgkin lymphoma. As clinicians prepared John for his first medical procedure, Beverly panicked. “When they put that oxygen mask on him, all I could see was my husband with that oxygen,” she says. “All I could think was, ‘Oh, God, I wish I had my husband here to help me go through this.’”

Beverly flew to the hospital's chapel and prayed for strength. “I was saying, ‘Lord, this is my son; this is my only son.’ And it was like God replied, ‘I gave my only son. I’m still in control; I’m still here.’ I said, ‘You’re right, Lord, this is your son. A load was lifted. And truly God of us.”

Hymn of thanksgiving

At St. Jude, John endured eight courses of intense, multi-agent chemotherapy. His mom says the care at St. Jude extended far beyond mere medical treatment.

“I have seen the money that people donate to St. Jude put into action,” she says. “When you come here, you’ve got this burden on you. Your heart is hurting and aching; you can’t think about home. Unfettered by anything except supporting your child.” Unless a person has gone through that, just can’t understand what a burden it takes off.

“I lost my husband, and we didn’t have any insurance,” she continues, “but St. Jude has not sent us one bill. Not one. And that in itself has just lightened the load.”

The Alston family felt a special bond to many staff members, but especially to John’s physician, John Sandlund, MD, of St. Jude Hematology-Oncology.

“I pray for John all the time,” Sandlund says. “He and his mom are always saying, ‘Thank you so much; thank you for helping us.’ What they don’t realize is that if anyone is getting something out of this, it’s what I get from them. They’re much more of an encouragement to me than I am to them.”

Improvisation

After finishing treatment in April of 2006, John left what he calls his "St. Jude family" to return home, finish his senior year of high school and make plans to further develop his musical skills. “I started playing the piano when I was about 5,” he explains. “I would copy what my sister played.”

About four years ago, he began studying music in earnest, and his repertoire expanded from gospel and popular genres into the classical realm. Now his sights are set on Juilliard. “That’s where I’d really like to go after graduation.”

John, who is leaning toward a career in music education or performance.

His caregivers at St. Jude are excited to see what the future holds. “John is talented almost beyond words,” says Gwen Anthony, RN. “He plays the piano like a dream; he’s a good spokesperson, and he’s modest.”

“John’s a gifted guy, in terms of personality and personal strengths and how he interfaces with people and deals with difficulty,” Sandlund adds. “And then on top of all that he happens to have this incredible gift of music. The sky’s the limit for him. It’s gonna be really fun to see where he tracks in life and what God has in store for him.”

Music with heart

Seated at the keyboard in Target House’s Amy Grant Music Room, John’s hands wander across the keys as he chats with his family. The jaunty, rollicking tunes of Scott Joplin morph into the poignant strains of “Through the Eyes of Love” and a dramatic theme from “Phantom of the Opera.” “But John’s first passion—like that of his father before him—is gospel music. “I’ll play the ending my mom likes,” he says, as he begins to perform. “It’s Well With My Soul.”

When peace, like a river, attendeth my way,

When sorrows like sea billows roll;

Whatever my lot,

Thou hast taught me to say.

It is well, it is well with my soul.

Beginning with a soft counterpoint, John slowly embellishes the melody, adding runs, glissandos, odd harmonies, new rhythms. The hymn grows in intensity, culminating in a storm that engulfs his mother in wave upon wave of sound. Buffeted by this musical tempest, Beverly feels the depths of pain John has endured and contemplates the possibilities that lie ahead. She gazes at her only son... and smiles.

beginning with a soft counterpoint, John slowly embellishes the melody, adding runs, glissandos, odd harmonies, new rhythms. The hymn grows in intensity, culminating in a storm that engulfs his mother in wave upon wave of sound. Buffeted by this musical tempest, Beverly feels the depths of pain John has endured and contemplates the possibilities that lie ahead. She gazes at her only son... and smiles. 
When Gastón K. Rivera, MD, recently looked into the smiling eyes of a little girl settled peacefully in a hospital bed in Santiago, Chile, his thoughts traveled back 22 years and more than 5,000 miles.

In 1984, in his office at St. Jude Children’s Research Hospital where he now directs the Chile Program for the International Outreach Program (IOP), Rivera wrote a protocol for children with acute lymphoblastic leukemia, which significantly improved overall survival. This protocol is still used in several countries worldwide and for the last six years has enjoyed success at Luis Calvo McKenna Hospital in Chile.

Forward strides

In 1999, after several years of intense preparation, St. Jude launched one of its first international outreach programs at Calvo McKenna. The collaborative effort focuses on bone marrow transplantation and limb-salvage surgery for children with the bone cancer osteosarcoma.

This spring the St. Jude Chile Program celebrated its 100th bone marrow transplant and the program’s ongoing success. Doctors there also performed their first haploidentical transplant, making Calvo McKenna, like St. Jude, one of only a handful of medical centers in the world that performs these complex transplants. Now, children who need bone marrow transplants and who do not have matched siblings or unrelated donors may undergo transplants using parental donations.

The first 100

“Celebrating the 100th transplant in Chile has been a dream come true,” says Rivera. “It goes to show you that a devoted group can perform anything it commits itself to do.”

“This program shows how great things can come from a small investment of St. Jude know-how and resources, when there are dedicated and talented partners in the host country,” says St. Jude Director and CEO William Evans, PharmD. “We think that the program in Chile will lead to similar programs throughout South America, fulfilling Danny Thomas’ vision of advances at St. Jude curing thousands of children all over the world.”

Evans joined a St. Jude group who traveled to Chile in March to congratulate the international team on their achievements, encourage them to keep up their extraordinary work and emphasize the program’s importance. While there, Evans and other St. Jude faculty also shared the latest St. Jude treatment and research advances. Evans is the hospital’s first director to visit Chile’s IOP center.

“Without St. Jude, we wouldn’t have this program,” says Julia Palma, MD, director of Calvo McKenna’s Bone Marrow Transplant Unit. “It has been six years, and now many children would have been turned away without the opportunity to live and doing well. We have transplanted 100 children with a good survival rate, 75 percent, and with a good quality of life, which is most important.”

Bridging time and place

For Rivera, the program’s ongoing success is personal. A native of Chile, he finds great satisfaction in serving as bridge between two worlds. “Through our collaborative research and international studies and protocols, St. Jude and Calvo McKenna can help the children from so many countries and states—here and there,” he says.

Rivera says he is proud that the Chile program is becoming a model for other St. Jude partner countries. Medical staff from other countries in the region are training in the bone marrow transplant unit in Santiago. “But most importantly,” he says, “the Chile program has helped many, many children who would literally have died without transplants.”

By Victoria Tilsley McDonough

Bridging Countries to Save Lives

One hundred transplants, many lives saved. Now, the International Outreach Program in Chile is working to increase this number exponentially.

At St. Jude, one dedicated team does whatever is necessary to ensure that children eat.

Hospital food.
Two words that have one commonly accepted meaning: “not so tasty.” At most health care facilities, food may not be exactly five-star quality, nor delivered on demand. At St. Jude Children’s Research Hospital, however, “hospital food” is a term that means made-to-order.

In a setting where young patients experience mouth sores and nausea, loss of appetite and unusual allergies, one team specializes in catering to nutritional needs and wants. Dietitians in the Clinical Nutrition department work closely with patients, families and the health care team to determine the best diet for patients receiving treatment.

“Our goal is to get patients to eat and to keep them as adequately nourished as possible,” says Ruth Williams, EdD, Clinical Nutrition director. “When children come to St. Jude, dietitians had more than 3,000 consults a year. The number has grown to more than 19,000 a year.

Among those thousands of consults are many kids who have experienced how Clinical Nutrition staff members go above and beyond in the name of food. Patients have special needs because of religious beliefs, cultural practices, specific diets, comforts or cravings. Staff members make arrangements for patients who must keep Kosher, who are Muslim, who eat only raw foods (Rastafarian), who ask for a specific brand name (Spaghetti O’s or SpongeBob SquarePants Kraft Macaroni & Cheese) or who crave Mommy’s home cooking.

“Once we made macaroni and cheese with a patient’s mother’s recipe,” Williams says.

If a child is not eating at all, dietitians ask about a favorite food—even if it means the child will consume only that food. “I had a patient who had an artichoke bush at his home,” says Kathryn Alexander, a nutrition support specialist. “The patient was not eating at all and asked for artichokes. I bought some, took them to the kitchen and worked with the chef on how to cook them. The patient ate artichokes every day.”

Williams has been at St. Jude since 1989 and has many stories about patient requests.

“One child really wanted an over-easy egg, which we do not serve,” Williams says. Because that kind of egg is not fully cooked, it may harbor dangerous bacteria. “We found a type of pasteurized egg that was frozen, and we flew it from New York. Another family who was Jewish had to keep Kosher, but their child did not, as is their custom if a person is sick. We got Kosher TV dinners for the parents so they could eat. No other place would do that.”

Patient Brayden Rydell craved a certain brand of ice cream bars. His mother, Brenda, remembers that her son was not eating at all.

“He had bad mouth sores while in the ICU,” she says. “He saw a commercial for ice cream bars and said, ‘I think I could try one of those.’ He was eating them faster than they could bring them.”

Brayden says he ate one every day.

“It melted in my mouth, so I didn’t have to chew it,” he says. “It was awesome to have a dietitian. Most of the time at other hospitals you can’t get what you want. At St. Jude, they’ll get it.”

Research has shown that well-nourished children have a higher ability to withstand infection and tolerate therapy than children who are undernourished. In 1997, St. Jude created a “room service” program. Like patrons in a hotel, patients staying in the hospital can order from a special menu whenever they are hungry. The year the program began, patient satisfaction with hospital food service improved by 35 percent due to the adoption of room service. Calorie intake rose 27 percent and protein intake increased by 17 percent.

“They can order breakfast and then call down at 10 a.m. for a snack and then eat lunch and then call down at 2 p.m. again,” Williams says.

Dietitians create menus based on patient needs, and Food Services staff help deliver the food.

“We have a group in our department who take the room service orders, put the trays together and deliver them to the patients,” says Judy Galloway, Food Services director. “We really place a lot of importance on getting the children what they will eat and what they like.”

Importance is also placed on researching different cultures and eating habits so that dietitians are prepared and knowledgeable about their patients.

“I’ve lived in different countries, so that helps me,” says Registered Dietitian Terezie Moshy. “I have lived in Chile, and we have had patients from Chile. So when they say they don’t like something, I know what they mean. A tomato here is not the same as a tomato there.”

As evidenced by the “Excellence in Clinical Nutrition Practice Team Award” given to them by the American Dietetic Association in 2004, the hospital’s Clinical Nutrition staff strive to meet their patients’ needs.

“At St. Jude, it’s not your typical dietitian’s job where you tell people what they can’t eat,” says Amy Lynch, a nutrition support specialist. “Here we’re asking kids, ‘Please eat.’”

Williams smiles.

“It’s our responsibility to feed them when they’re at the hospital,” she says. “And if it means doing something a little extra, then we’ll just have to do that.”

Dietitians work side by side with Food Services staff to purchase and prepare meals for inpatients.

“We have a philosophy at St. Jude that our children should have what they need and what they want,” Williams says. “We try to look at the whole picture and what’s going to be best for the patient. It’s good for a patient to eat, and it’s good for the family to see the child eat.”

While dietitians work with patients on an as-needed basis, they are also an integral part of certain treatment plans. When Williams came to St. Jude, dietitians had more than 3,000 consults a year. The number has grown to more than 19,000 a year.

At most health care facilities, food may not be exactly five-star quality, nor delivered on demand. At St. Jude Children’s Research Hospital, however, “hospital food” is a term that means made-to-order.

“Once we made macaroni and cheese with a patient’s mother’s recipe,” Williams says.

If a child is not eating at all, dietitians ask about a favorite food—even if it means the child will consume only that food. “I had a patient who had an artichoke bush at his home,” says Kathryn Alexander, a nutrition support specialist. “The patient was not eating at all and asked for artichokes. I bought some, took them to the kitchen and worked with the chef on how to cook them. The patient ate artichokes every day.”

Williams has been at St. Jude since 1989 and has many stories about patient requests.

“One child really wanted an over-easy egg, which we do not serve,” Williams says. Because that kind of egg is not fully cooked, it may harbor dangerous bacteria. “We found a type of pasteurized egg that was frozen, and we flew it from New York. Another family who was Jewish had to keep Kosher, but their child did not, as is their custom if a person is sick. We got Kosher TV dinners for the parents so they could eat. No other place would do that.”

Patient Brayden Rydell craved a certain brand of ice cream bars. His mother, Brenda, remembers that her son was not eating at all.

“He had bad mouth sores while in the ICU,” she says. “He saw a commercial for ice cream bars and said, ‘I think I could try one of those.’ He was eating them faster than they could bring them.”

Brayden says he ate one every day.

“It melted in my mouth, so I didn’t have to chew it,” he says. “It was awesome to have a dietitian. Most of the time at other hospitals you can’t get what you want. At St. Jude, they’ll get it.”

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Catering to Patients


At St. Jude, one dedicated team does whatever is necessary to ensure that children eat.
In the last handful of years, Karri Morgan has learned that if you take the wheels off a Radioflyer wagon, it makes a fantastic sled. She has learned the difference between faith and bargaining and that “volunteer” is a weird word, its root definition not even touching all that it encapsulates. But the Target House manager has also found that listening—and learning—are the most essential skills of all.

In a Target House living room one day, Morgan spotted a 4-year-old patient with her hands pressed against the glass of an aquarium. Morgan squatted down next to the girl, becoming small, too, and started telling her about the striped fish, the puff-cheeked one, the baby fish wiggling happily behind the mommy fish. The girl had recently lost both her eyes from retinoblastoma, a rare eye cancer. Without saying anything, the patient took Morgan’s hands and pressed them against the glass. Then, she politely closed Morgan’s eyes for her. Without a word, this little girl showed Morgan what it felt like to be her. They stood there, together, their hands spread like delicate starfish against the cool glass.

Humble heroes

For families heading to St. Jude Children’s Research Hospital for the first time—their children’s diagnoses reverberating in their ears like terrifying shrieks—packing bags, closing windows and locking the doors to home can be wrenching. Home, after all, is where family is—where the hues of everyday life eddy around in a swirl of children’s laughter, wagging dog tails and familiar voices. Home is where that lovely, soft feeling of safety exists. No one expects to find home at a pediatric hospital for children with catastrophic diseases.

Until 1999, many of the families whose children were in long-term treatment at St. Jude stayed in hotel rooms, an enormous annual cost for the hospital since some treatment can extend as long as three years. But with the emphatic nod of one generous and socially enlightened corporation, families have come to live in Target House—a home-away-from-home.

Elephants, with their wizened skin and large sagacious eyes, represent family, long life, strength and playfulness. In many cultures, these pachyderms are symbols of luck. This elephant fountain captures the spirit of Target House, where families live, play and heal. A duplicate of the fountain, designed in copper verdigris by artist Michael Graves, stands inside the Target corporate headquarters in Minneapolis.

Based on the input of the Teen Council—a committee of teenaged patients and siblings who wanted a say in the renovation of their special Teen Room—Target planned for a designer to work with the group to create a refuge to match their vision. Once again, Target, generous beyond description, brought that design to fruition—complete with huge plasma TV, arcades and out-of-this-world seating. It’s all about hanging out, after all.

Carnivals and care

Like the Energizer Bunny™, Target keeps on giving—not just material and monetary gifts but, more importantly, support, care and friendship. In the Teen Room, a floor-length, 4-foot-wide plasma TV and a 10-foot-long couch are the centerpiece. Two Jenison arcades stand at the end of the room, providing a place for kids to unwind, play and interact. For the first time, Target also offers a place for parents to relax.

Target is much more than a long-term housing facility: It’s a home-away-from-home.

By Victoria Tilney McDonough

On Target

It’s much more than a long-term housing facility: It’s a home-away-from-home.

PHOTOS BY ANN-MARGARET HEDGES

On Target—Continued
Target House, where families live, play and heal. “It’s an honor for Target to be a partner with St. Jude in its never-ending quest to find a cure for every child,” says Laysha Ward, vice president of Community Relations at Target. “And while we are often credited for bringing happiness to St. Jude patients and families at Target House, it is their amazing stories of courage and perseverance which inspire us each and every day.”

A perfect balance
In addition to all the Target events, families are also treated to countless volunteer events. People seem to come out of the woodwork when it comes to brightening the lives of St. Jude patients and families. Volunteers host several dinners a week, pool tournaments, Bingo nights, arts-and-crafts projects and some sweet events, too, like cookie-decorating. They even arrange for weekly visits from a swanky local hair salon. Volunteers help make the house tick—from showing foreign families how to use the laundry machines to taking time to color with a little child.

“When you leave home with a sick child, you are terrified. You are stripped from everything you know—home, family, friends, everything that means ‘normal,’” says Bridget Hart, mother of 13-month-old Clay, diagnosed with acute lymphoblastic leukemia. “So being able to do your family stuff—cook dinner in your own kitchen, read bedtime stories to your baby in your own room—is priceless. And when you do need a community, it’s there. Here, when a mom says ‘I know what you’re going through,’ she does. It will be hard to leave Target House and St. Jude.”

Target House seems to have found the perfect balance between offering families the privacy and normalcy they need as family units and the community of others who truly understand what they are experiencing. To replenish his spirit, a patient might spend some time practicing the piano in the Army Grant Music Room. A mother’s child might escape in a book in the Tiger Woods Library. A father might sweat off his sadness in the weights to taking time to color with a little child.

The beauty of strangers
The walls of Morgan’s office look as if they are covered with colorful shingles. Taped and pinned on every conceivable inch are hundreds of photographs, drawings and notes to those two girls continue to keep in touch with the family through the walls of Morgan’s office look as if they are covered with colorful shingles. Taped and pinned on every conceivable inch are hundreds of photographs, drawings and notes to kids. Here, when a mom says ‘I know what you’re going through,’ she does. It will be hard to leave Target House and St. Jude.”

When Target House Manager Karri Morgan asked a patient leaving Target House for home what he would most miss, he said, “I am going to miss my friends here because no one knows me at home. And the doctors because they saved my life.”

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Morgan remembers two little girls who every day slipped get-well notes in Spanish under the door of a tiny foreign baby born with cancer. “I caught them one day running back across the hall to their apartment. I found out that they made these daily cards for ‘their baby,’” she says. “I think it’s that kind of beauty, the beauty of strangers, that makes this house work like an enormous heart. And the knowledge that we are all in it together.” Years after that little baby boy sadly lost his fight, those two girls continue to keep in touch with the family through cards and letters. When Target House Manager Karri Morgan asked a patient leaving Target House for home what he would most miss, he said, “I am going to miss my friends here because no one knows me at home. And the doctors because they saved my life.”

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Perspective

The Gift of Giving

"A gift inspires another gift, and a miracle inspires the next miracle. It’s got to start somewhere; it might as well start with you."

By Scott Hamilton

It’s funny how every event in your life leads you to the next thing. When I was a kid, I had a mysterious illness that caused me to stop growing. Without that childhood illness, I’d probably be much taller than I am today; I might have had much more physical development and might not have ended up being a skater. If I hadn’t been skating, obviously my life would have been a lot different. So every event puts you where the next event can shape the next aspect of your life.

Several years ago, I had testicular cancer, followed by a bout with a non-cancerous brain tumor. I lost my mother to cancer, and so the importance of cancer research was infused in me at a very early age. When I had an opportunity to become involved with St. Jude Children’s Research Hospital and Target House, it just seemed like a natural fit. Everything I had experienced—as a child and as an adult undergoing cancer and chemotherapy and surgeries—had led me to this place. I felt like I could understand what the kids were going through and I could truly be empathetic to their issues.

My wife, Tracie, and I have a 2½-year-old son named Aidan. Suddenly the stakes have gotten even greater for me to find new research dollars and help create awareness of St. Jude and Target House. The more I can do, the better I hedge my bets to make sure that if Aidan were ever to have an issue, that something I participated in might have created the miracle that would save his life.

You may never know the people whose lives you’ll touch when you help fund medical research. We all have an opportunity to really roll up our sleeves and get involved in something that is much more important than ourselves. The greatest gifts ever given are those to whom the recipients will never know their origin.

Danny Thomas said, “There are givers and takers in the world. The takers eat better, but the givers sleep better.” Knowing that you can give of yourself for something that will go beyond your time on this planet is truly an extraordinary gift and something that will allow you—as Danny would say—to sleep better.

A gift inspires another gift, and a miracle inspires the next miracle. It’s got to start somewhere; it might as well start with you.

St. Jude is built on the highest levels of giving. Whether it’s a dollar or 5 or 20 or 100 or a million—whatever you can do to participate is bricks and mortar, it’s medicine, it’s time, it’s nursing, it’s doctors. Everything that you can do makes a difference.

Olympic gold medalist Scott Hamilton is a longtime supporter of St. Jude and Target House. A cancer survivor himself, the figure skating icon also has an active career as an actor, producer, author, sports analyst, motivational speaker and philanthropist.

For Bob Gardner, the more he learned about St. Jude Children’s Research Hospital, the more he wanted to help. Bob made his first contribution back in 1983, following his retirement from a successful career with the DuPont Company.

As his giving continued, he found out more about the advances in research that were steadily improving survival rates for children with cancer and other catastrophic diseases being treated at St. Jude. Then in 1993, a few years after his wife Mary passed away, Bob decided to significantly increase his support by funding the first of a series of generous charitable gift annuities. He explained, “My financial planning had always been organized around the expectation that Mary would outlive me. When that changed, I concluded that I could afford to do more for the charities I care about most.”

Call the Gift Planning department today at 800-427-6750 or e-mail us at giftplanning@stjude.org.