St. Jude Children's Research Hospital
ALSAC • Danny Thomas, Founder

Promise

Summer 2007

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Promise

A publication of St. Jude Children's Research Hospital Summer 2007

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Promise
is a quarterly publication of the
Department of Public Relations
St. Jude Children's Research Hospital
332 N. Lauderdale St.
Memphis, Tennessee 38105

St. Jude Children's Research Hospital's mission is to advance cures, and means of prevention, for pediatric catastrophic diseases through research and treatment. Consistent with the vision of our founder, Danny Thomas, no child is denied treatment based on race, religion or a family's ability to pay.

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On the cover: St. Jude patient Brooklyn Graves-Bingle. Story on page 8; photo by Peter Barta.

Highlights

PETER BARTA

Patient Stephan Boehme meets supermodel, television personality and St. Jude supporter Daisy Fuentes during the fifth annual FedEx/ St. Jude Angels & Stars Gala in Miami, Florida. The evening raised $300,000 for St. Jude. Fuentes, the event's celebrity chair, was joined by legendary singer-songwriter and Grammy® Award winner José Feliciano, pop singer and multi-platinum recording artist Cristian Castro, Grammy® Award winning Cuban singer and composer Albita, No. 1 Billboard® ranked pop-tropical singer Fanny Lu and Jade Alexander of CBS4 News in Miami.

Leukemic cells' safe haven

The cancer drug asparaginase fails to help cure some children with acute lymphoblastic leukemia because molecules released by certain cells in the bone marrow counteract the effect of that drug.

St. Jude researchers showed that specific cells in the bone marrow create a protective niche for leukemic cells by releasing large amounts of asparagine, an amino acid that nearby leukemic cells must have to survive but do not make efficiently. This extra supply of asparagine helps leukemic cells survive treatment with the drug asparaginase.

Dario Campana, MD, PhD, of Oncology and Pathology is senior author of a report on this study that appears in the April 2007 issue of *The Journal of Clinical Investigation.*

Cure4Kids milestone

The St. Jude *Cure4Kids* Web site now has more than 10,000 users from 155 countries. Established in 2002 as a part of the International Outreach Program, the *Cure4Kids* Web site brings the latest medical knowledge on the treatment of pediatric catastrophic diseases to health care providers in countries with limited resources.

The site offers a digital library, on-demand seminars with slides and audio in several languages, and other resources.

"Cure4Kids now contains 900 seminars, 25 online courses, 20 international conferences and 120 international groups that meet online," said Yuri Quintana, PhD, of International Outreach. "The content has been accessed more than 1 million times."

Learning from survivors

Results from the longest follow-up study ever done of childhood acute lymphoblastic leukemia (ALL) survivors show the importance of long-term monitoring of former patients to identify complications they are at risk for developing later in life and to modify current treatments to reduce those risks.

A report on this work appeared in *Journal of the American Medical Association* (JAMA) in March of 2007. Nobuko Hijiya, MD, of Oncology is the article's first and corresponding author.

Enzyme recruitment

Parents might one day give their children a weekly treatment with a nasal spray of virus enzymes to prevent them from getting severe middle ear infections, based on results of a study done by investigators from St. Jude and The Rockefeller University in New York. Such a treatment would kill the disease-causing bacteria without the use of antibiotics, thereby avoiding the problem of antibiotic resistance.

A report on this study appears in the March 2007 issue of the online journal *PLoS Pathogens*. Jonathan McCullers, MD, of Infectious Diseases is the paper's first author.

Excellent center

St. Jude has been designated one of six Centers of Excellence for Influenza Research and Surveillance funded by the National Institute of Allergy and Infectious Diseases (NIAID), a part of the National Institutes of Health. Robert Webster, PhD, of Infectious Diseases is principal investigator for the program at St. Jude.

The goal of the centers is to help the federal government prepare for and respond to seasonal influenza as well as outbreaks of animal influenza that might cause pandemics, or worldwide epidemics, in humans.

Predicting decay

St. Jude investigators say they have found the best way for predicting when patients will need future surgery to repair hip joints that have deteriorated because of pediatric leukemia or lymphoma treatment.

The investigators found that if more than 30 percent of the head of the bone fitting into the hip socket is deteriorated, it is at high risk of collapsing and requiring reconstructive surgery within two years. Intensive use of corticosteroid drugs has been implicated in development of bone deterioration. However, these drugs have helped raise survival rates of children with pediatric leukemia and lymphoma, and currently there is no adequate substitute for their use.

A report on this work appears in the April 20 issue of *Journal of Clinical Oncology*. Sue Kaste, DO, of Radiological Sciences is the paper's senior author.

Seeing double

St. Jude investigators had a molecule's eye view of the human cell's DNA repair kit as it assembled on a double-strand break to link together the broken ends. Double-strand breaks are ruptures that cut completely across the twisted, ladder-like structure of DNA, breaking it into two pieces.

Using a technique developed for this project, the researchers determined when repair proteins arrived at or around the DNA break. A report on this work appears in *Nature Cell Biology*, May 2007. The findings are important because disruption of the precise movement of these repair proteins can cause mutations, cell death or cancer, and the ability to track the process closely will give researchers critical insights into what can go wrong with DNA repair. Michael Kastan, MD, PhD, St. Jude Cancer Center director, is the paper's senior author.

Toxic inheritance

St. Jude investigators have discovered inherited variations in certain genes that make children with acute lymphoblastic leukemia (ALL) susceptible to the toxic side effects caused by chemotherapy medications. The researchers showed that these variations occur in specific genes known to influence how drugs work in the body and how much drug is needed to have its intended effect. The findings are important because side effects in ALL can be life threatening and interrupt delivery of treatment, increasing the risk of relapse. New insights gained in this study could help individualize ALL chemotherapy according to a patient's inherited tendencies to develop toxic reactions to specific drugs.

Mary Relling, PharmD, chair of Pharmaceutical Sciences, is senior author of a report on this work published in the May 15, 2007, issue of *Blood*.

Repair of DNA by *Brca2*

St. Jude investigators have gained some of the first major insights into how certain genes known to prevent cancer also guide the nervous system's development before birth and during infancy by repairing DNA damage.

The researchers demonstrated that the *Brca2* gene plays a dual role in the developing nervous system, eliminating errors in the DNA of newly made copies of chromosomes and suppressing the onset of the brain cancer medulloblastoma. Peter McKinnon, PhD, of Genetics and Tumor Cell Biology is senior author of a report on this work in the May 3, 2007, online issue of the *The EMBO Journal.* ●

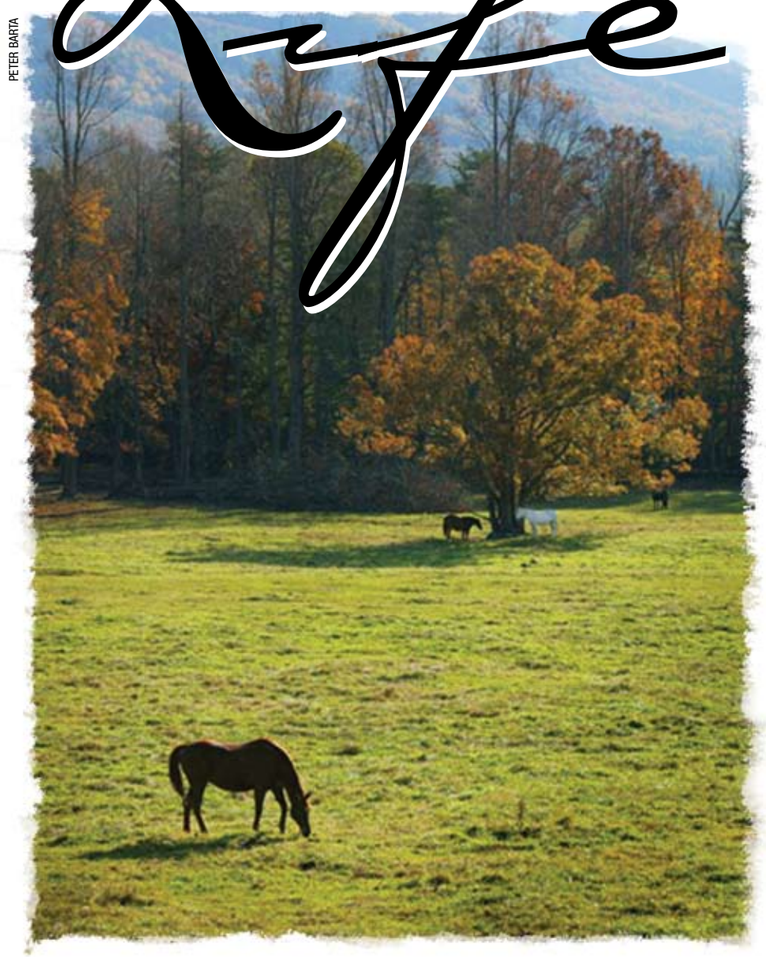
10 Things No One Tells You About Pediatric Cancer Treatment

By Catherine Greenslade

1. You will age 10 years in one day—diagnosis day.
2. You will age another 10 years during treatment.
3. You will age yet another 10 years waiting for that first post-treatment check-up.
4. You will not be able to remember anything that involves something other than your child's blood counts and appointments.
5. Frozen dinners taste really good, if you're lucky enough to be hungry.
6. Insomnia becomes a way of life.
7. No amount of concealer will hide those dark circles. Consider them a fashion statement.
8. Gatorade® may go down one color, but it comes up an entirely different color.
9. "Waiting" is an art form in which you will become an expert.
10. Your child will become mature far beyond her years, often wiser than you will ever be.

Catherine Greenslade is the mother of Emily Miller Land, a survivor of the bone cancer osteosarcoma. To read Emily's story, visit www.stjude.org/news and click on "Promise Magazine." Emily's story appeared in the winter 2005 edition, page 22.

A Beautiful Life



PETER BARTA

Doug and Mary Calvert double their donations to St. Jude through the hospital's matching gifts program.

By Lynda Nance

Alive with white violets and bergamot flowers, Dawson Springs in western Kentucky is a beautiful place. It's easy to understand why Doug and Mary Calvert chose to make their life here after they married in 1965. The couple has known each other from the time they were children. Doug was born less than four miles away, in the heartland of the state.

"We've lived here our whole lives," Mary explains.

It is clear that once they dedicate themselves to something, the Calverts stick with it. This is true not only about their hometown, but also their favorite charity. To date, the Calverts have donated a total of $38,060 to St. Jude Children's Research Hospital.

The Calverts have been St. Jude donors since 1977. They were drawn to the hospital because of Danny Thomas' promise that no child would ever be turned away due to a family's inability to pay.

Though they never had children of their own, the couple wanted to do something specifically for children. St. Jude was a natural choice.

In 1990, when Doug started working for General Electric, the couple's donations continued, but Doug also signed up for the GE Foundation's matching gifts program. For each dollar the couple gives to St. Jude, GE pitches in another dollar.

Joining the matching gifts program enables the couple to double their St. Jude giving. And the Calverts aren't the only ones at GE making St. Jude donations. Kathleen Mayglothling, a program manager with the GE Foundation, says that since 2005 the foundation has matched approximately $325,000 in gifts to St. Jude by employees and retirees of GE.

The Calverts have another, bittersweet reason for donating to St. Jude. In 1992, Mary became ill with a rare neurological disorder that causes muscle rigidity and a heightened sensitivity to stimuli such as noise and touch, which can set off muscle spasms.

"We loved to horseback ride," she says. "But after I became sick, we had to stop." She pauses. "That's really the main reason we give. I had 42 healthy years; I know what it's like to be healthy. St. Jude is a worthy cause because these kids need all the help they can get."

For more information about matching gifts, please visit www.stjude.org/matchinggifts. ●

A Marriage of Generosity and Vision

By Betsy Taylor

One couple funnels shared energy and resources into saving the lives of children.

GREAT couples achieve more together than they may have done separately. Parviz Tayebati, PhD, and his wife, Susan, of Weston, Massachusetts, are one couple whose interests and impressive accomplishments converge to serve a greater purpose.

Married in 2002, Parviz and Susan were introduced by friends, and as luck would have it, they clicked. "I think the timing was just really right for us," Susan says. "We were both at a point in our lives where we were ready to settle down." It was clear to those who knew them that they shared the same fundamental philosophies on life and had similar senses of humor.

With a master's degree in theoretical physics and a doctorate in quantum electronics, Parvis has a genius for turning concepts into practical realities for the benefit of many. He saw the promise of fiber optics when few did and helped expand its applications to include everything from telecommunications to defense. He belongs to numerous professional societies, has published scores of scientific papers and has 25 patents and patents pending for fiber optic communications devices and subsystems.

Susan's life choices reveal a desire to understand human systems and a commitment to improve them. She received a bachelor's degree in economics and sociology from the University of Massachusetts in Amherst and is currently at work obtaining a graduate degree in speech language pathology at Emerson College in Boston.

They have concentrated their formidable energy and resources to funding children's causes through the Tayebati Family Foundation, which they diligently administer. Susan and Parviz are also devoted parents to their beloved 2-year-old son.

The couple knew they wanted to give to St. Jude Children's Research Hospital when they learned that no child is ever turned away because of the family's inability to pay. They also recognized how important it is that St. Jude pursues the development of revolutionary vaccines and drugs focused exclusively on saving children's lives. "These two items really impressed me," Parviz says.

Their $1 million commitment to the hospital supports the work of the Chemical Biology and Therapeutics department, which speeds science discoveries into treatments and cures for children who suffer from catastrophic diseases.

"I appreciate that the research done at St. Jude is not separate from the clinical practice; it's intertwined," Parviz says. "The researchers apply their discoveries to actual patients right away, in real time."

The couple's generosity and vision will have a real and lasting effect, helping to save the lives of children from all walks of life for years to come.

To learn about making a gift to St. Jude or other planned giving opportunities, call Gift Planning at (800) 395-1087 or e-mail giftplanning@stjude.org. ●

Thinking about when she was first told she has Hodgkin disease, Rhondalyn Aklin (at right) says, "I didn't know much about cancer at that time. But I prayed about it, and I'm not scared right now."

Timing is Everything

By Lois M. Young

New St. Jude affiliate clinic brings care and comfort to patients in Alabama.

PHOTOS BY JEFFREY HANSHAW, HUNTSVILLE HOSPITAL

In February 2007, 16-year-old Rhondalyn Aklin was active on her school step team, training to be a certified nursing assistant and looking forward to working so she could save money for a car—a vintage Ford Mustang. Then she noticed that one of her lymph nodes was swollen, and a doctor removed the growth. "They told us it was Hodgkin disease," Rhondalyn recalls.

It turns out that one of her classmates at a small private school in Huntsville, Alabama, is a patient at St. Jude Children's Research Hospital.

Rhondalyn's dad, Ronald, remembers, "I went to the mother of the St. Jude patient and tried to find information that might help us."

"They told us how much they appreciated St. Jude and what good care their son was receiving," says Rhondalyn's mom, Gwendolyn. "After talking with the other student and praying with him, Rhondalyn felt that St. Jude was where she needed to go."

As fate would have it, St. Jude had just opened a new affiliate clinic at Huntsville Hospital for Women and Children. The clinic doctor sent Rhondalyn to St. Jude in Memphis for her initial work-up and first chemotherapy treatment. But thanks to the new clinic, she receives most of her treatments close to home.

Idea sparks destiny

Before the Huntsville affiliate opened, St. Jude already had affiliate clinics in Johnson City, Tennessee; Peoria, Illinois; and Baton Rouge and Shreveport, Louisiana.

"The main purpose for having affiliate clinics is to allow patients to receive most of their care near home," explains Cindy Burleson, St. Jude Domestic Affiliate director. The arrangement benefits St. Jude by increasing the number of patients who enroll in the hospital's research protocols, or scientific treatment plans. Because some affiliate patients can go home between treatments, it frees up housing space and travel funds for patients who need to come to Memphis. St. Jude and the affiliates share the cost of clinic staff salaries, leased space, supplies and start-up costs.

In 2005, a Huntsville emergency room doctor read about the affiliates and thought, "Why can't Huntsville do the same thing?" His interest led to a conference call between Huntsville Hospital and St. Jude leaders. About a year later, the institutions announced the addition of a St. Jude affiliate clinic in Huntsville.

"We are very, very selective about where we open clinics," said St. Jude Director and CEO William Evans, PharmD. "When we met the leadership and clinical staff at Huntsville Hospital for Women and Children, we knew that we had found a partner that shared our mission and values."

Building on fate

St. Jude and Huntsville Hospital for Women and Children found the ideal clinic director in Lucille Ferrante, MD. She had worked in Huntsville as a pediatrician before becoming a pediatric hematology-oncology fellow at the Medical University of South Carolina in Charleston. Ferrante was excited about the prospect of returning to Huntsville. She finished her fellowship in July, accepted the St. Jude Clinic position in August and gave birth to twins (a boy and girl) in early September. "I couldn't have written it any better," Ferrante told *The Huntsville Times* newspaper.

The hospital's administrators worked with Ferrante to select the clinic staff, and "the Domestic Affiliate team trained them the St. Jude way," Burleson says. Ferrante took the lead with further education once she came on board. Huntsville Hospital's Vice President of Women's and Children's Services Paula W. Lucus and Director of Children's Services Cathy Hubler also played crucial roles in establishing the program.

All clinic staff members and some inpatient nurses from the hospital traveled to St. Jude in Memphis for training. Several St. Jude staff went to Huntsville to help with the clinic's training and set-up needs.

Patients reap benefits

St. Jude covers the cost of all co-pays, deductibles and outside professional services for affiliate patients. Huntsville Hospital covers services at Huntsville Hospital for Women and Children that are not paid by insurance. Of course, if patients must travel to Memphis for part or all of their care, St. Jude pays for that care, as well as for travel, housing and food.

Although Rhondalyn receives most of her treatments in Huntsville, she travels to Memphis every four weeks for advanced testing and one chemotherapy treatment.

"You pray about things and try to leave it in God's hands," Gwendolyn says, "But I have to say how much I appreciate what the people at St. Jude do, both in Huntsville and in Memphis. Rhondalyn's treatment is right on track, and they make you feel like you are connected—part of a family. They never leave you wondering what is going to happen next." After completing all her chemotherapy treatments, Rhondalyn will return to Memphis for several weeks of specialized radiation therapy.

Destined to succeed

At the three-month mark, the Huntsville affiliate clinic was already caring for 28 new hematology patients and nine new oncology patients. In addition, Huntsville had referred 13 patients to St. Jude in Memphis.

"Having the children treated closer to home is better for the child, better for the family and can aid in better treatment outcomes," says Joseph Mirro, MD, St. Jude chief medical officer and medical director for the affiliate clinics.

"We really see the affiliate program as a win-win situation for everyone involved," Burleson says, "and the biggest winners are the patients and families."

The Acklin family agrees. Rhondalyn looks forward to the day when she can go back to school, join her friends on the step team and work hard for her dream car—but until then, she will be able to fight most of her cancer battle close to home surrounded by family and friends. ●

PHOTOS BY PETER BARTA

St. Jude researchers craft a special blend of treatment to conquer a rare bone disease.

A Tall Order

By Elizabeth Jane Walker

The guttural hiss of a cappuccino machine, the low murmur of conversation and the pulse of ambient music muffle the tiny voice that emanates from beyond the cash register. Perplexed, a barista leans over the counter and peers down. Smiling up is a delicate, 3-year-old girl with milky skin and beribboned pigtails.

In a voice that retains the innocence of babyhood, the child repeats her request.

"My mommy would like a grande nonfat marble mocha macchiato, and I would like her whipped cream," says Brooklyn Graves-Bingle.

Brooklyn's cherubic sophistication elicits a proud grin from her mom, Danie. "I know adults who can't even order that drink," Danie says.

Danie and Brooklyn nearly always drop by the nearest coffeehouse when they go shopping near their home in central Washington. The irrepressible "fashion diva" even names the outfits she acquires on those outings. For instance, Brooklyn's "punk outfit" consists of black, footless tights, a pink mini skirt and a black-and-white striped shirt. Depending on her mood, she might pair that ensemble with pirate boots or a tutu and ballet slippers.

It's hard to believe that only a few years ago, this delightful child was given a 100 percent chance of dying by age 10. Sitting at a café table with her beautiful daughter, Danie swallows a memory of that day that's as pungent as the darkest espresso.

Trouble brewing

Soon after Brooklyn was born in July of 2003, Danie and Jed became increasingly concerned by their daughter's failure to gain weight, her constant ear infections and jerky eye movements. When two lumps arose in Brooklyn's abdomen, the infant underwent a battery of tests for leukemia, anemia and a host of other diseases. Finally, the family consulted Vikramjit Kanwar, MD, an Oregon hematologist-oncologist who had undergone training at St. Jude Children's Research Hospital. With help from his former colleagues, Kanwar identified the problem and called Danie.

"Brooklyn has a disease called malignant infantile osteopetrosis," he said. "Don't go look it up on the Internet; wait until you come in and talk to me." His warning disappeared like smoke as Danie hung up the phone and logged onto the Web. Fingers flying across the keyboard, she pulled up page after page of dire predictions.

"I burst into tears," she recalls. "The Internet said that Brooklyn would probably not live to be 1 year old. She would be blind, deaf and have painful deformities of the bone."

Island of hope

When Danie and Jed met with Kanwar, he referred them to St. Jude. Upon arrival in Memphis, the family met with Kimberly Kasow, DO, of St. Jude Bone Marrow Transplantation. She explained that malignant infantile

osteopetrosis is an inherited bone disorder in which cells called osteoclasts fail to do their job. In healthy bone, osteoblasts constantly make new bone and osteoclasts break down and dispose of old bone. In this extremely rare disease, bone cells continue to accumulate, which means that the bones cannot accommodate healthy bone marrow and nerves.

"It's a very rare disease," Kasow told them. "If about 4 million kids are born in the U.S. each year, you may be talking about 20 who are born with it."

Most children with osteopetrosis die because of infections prompted by bone marrow failure. As osteoblasts make more bone, the bone marrow becomes fibrous and cannot make new cells. The couple learned that their daughter's bones were 32 times more dense than those of a normal child her age.

Exhausted and overwhelmed, Jed and Danie struggled to understand the cascade of words that flowed around them. But amid this tumult of information, one island of hope emerged: the words "possible cure through a transplant."

Race against time

When Brooklyn arrived, St. Jude was in the process of creating a new protocol, or scientific treatment plan, for osteopetrosis. As soon as the protocol was approved, clinicians began searching for a blood stem cell donor. But time was their enemy. Every day, the density of Brooklyn's bones increased, squeezing out healthy marrow and reducing her ability to fight infection.

Kasow knew that if they took the time to find a donor through the National Marrow Donor Program, her disease could progress too far. But there was another option. St. Jude had pioneered a process through which some parents could donate blood stem cells for their children. Jed and Danie underwent testing and waited for an answer.

"I don't think I have ever seen doctors dance into a room," says Danie, but Dr. Kim quite literally frolicked into the examination room to tell us that I was a nearly perfect match. It's surreal to think that we were quite giddy and excited to hear words that no parent should ever have to hear."

Although they were ecstatic about the news, Danie and Jed understood the risks all too well.

"A transplant is a treatment that could kill her," Danie says. "We had a choice. We could keep her at home and let her die slowly, or we could give her a chance with the transplant. If she had the transplant, one of two things could happen: She could live, or her life could have meant something and could benefit other families and other kids who were going through the same thing."

Kasow understood their feelings. "We tell parents that when they step foot through the doors of St. Jude, it is life altering. You don't know whether you are going to leave with your child or not. Transplant is not easy. But without a potentially curative transplant, Brooklyn would have died."

Transplant and epiphany

The happy news arrived just in time. At her first birthday, Brooklyn was the size of a 6-month-old. "She wasn't walking or talking," Danie recalls. "She would sit hunched over, and she wouldn't reach for any toys. She didn't play or know how to interact. She would just sit and stare at you, and that was it."

"Kids with this disease just don't feel well," Kasow explains. "Their body does not make red blood cells, so they are anemic and feel tired. Their liver and spleen take up extra space and cause belly pain. They can't sleep well because of obstructive sleep apnea caused by having small jaws and small chest walls."

Brooklyn's treatment at St. Jude demanded the talents and expertise of a massive team of people including speech therapists to help with language skills; ophthalmologists to treat her vision problems; audiologists to evaluate hearing loss; technicians to process the cells; dieticians to optimize her nutrition; physicians who specialize in treating sleep apnea; physical therapists to help her gain mobility; and researchers to study the genetic mutation that spawned the disease.

"Kids with osteopetrosis really deserve to have a multi-disciplinary team approach," Kasow says. "Treatment entails more than just giving chemo and cells and antibiotics; we are also helping them develop as individuals. That's what we strive to do at St. Jude, and we do it well."

Before undergoing the transplant, Brooklyn's existing bone marrow had to be destroyed so that her mother's cells could engraft and create a new, healthy immune system. Brooklyn underwent eight days of high-dose chemotherapy to achieve this goal. Meanwhile, Danie was taking a drug to stimulate her own body to create stem cells. The drug made Danie intensely sick.

"I would compare it to an absolutely crippling case of arthritis," she recalls. "It makes your bones feel like they are going to explode. I was downstairs taking the G-CSF shots and morphine because it made me hurt so much. Brooklyn was on morphine too, because she was so sick. And Jed was constantly running between the two of us trying to keep up. It was pretty dreadful."

Until that time, Danie had been trying to maintain her career in the hotel industry. Jed was a new college graduate who had not yet entered the workforce. The family desperately needed income and health insurance. Danie was frazzled and stressed and overwhelmed. One day during chemotherapy, she sat by Brooklyn's bed watching her sleep. Tiny fingers curved against the plump peach of Brooklyn's cheek; a translucent pulse beat in the hollow of her tiny throat.

"At that point, I realized that jobs come and go, but that I might not have a lifetime with Brooklyn," Danie says. "I just needed to be with her—not try to work and support us. St. Jude would cover her care if we lost the insurance. We were staying at Target House, so we didn't have the extra financial stress of paying for housing. It suddenly hit me that I could focus on getting Brooklyn better without worrying that we would owe $3 million in medical bills. It was much more than a relief—it was huge."

Sunbeams and silver kisses

Brooklyn sailed through the transplant process with few problems. Instead of the expected 100-day inpatient stay, she was hospitalized only 32 days. The toddler began noticing shiny silver balloons in one area of the hospital. She insisted that her mommy pause by each one so that she could kiss her reflection.

Before Brooklyn's transplant, her St. Jude speech therapist had taught her sign language. But now Brooklyn began to speak. She chattered and laughed and played with abandon. When strangers quizzed her about the origin of her beautiful curls, she replied, "From chemo."

Danie and Jed laugh fondly at their daughter's exuberance and imagination. For instance, Brooklyn has three small toy ponies. The pink one is named Sunbeam; the yellow one is Platelet. The white one's moniker is Box of Soap. Brooklyn eagerly anticipates her checkups, because that's when she can see "Doctor Kimmie" and "Nurse Debbie" and other special staff members.

The attraction is mutual. "She's one of our miracles," says Debbie Cherry of the Ambulatory Care Unit. Cherry was one of the first people to meet Brooklyn when she arrived at St. Jude in 2004. "I saw Brooklyn take her first steps. You watch the kids grow, and you watch them do so well and it just touches your heart."

Kasow says the future looks bright for Brooklyn.

"Her mom's blood-making cells took hold and grew, and Brooklyn's blood-making cells are now 100 percent her mom's," Kasow says. "Brooklyn's bone marrow has actually remodeled. Before the transplant, it was very fibrotic. We took pictures of her bone marrow a year after transplant. The pathologist called me and said, 'If I did not know this was an osteopetrosis child, I would have said that this was a normal bone marrow.' She has come a long way and is an inspiration to other families who have children with infantile osteopetrosis."

Today, Jed is a civil engineer and Danie works in the health care field—a career change that was a natural outgrowth of her time at St. Jude. "I started working in the health care field because I needed to do something that meant something at the end of the day," she explains.

But at the end of the proverbial day, Danie and Jed are, above all, thankful.

"You can't sum up our St. Jude experience," Danie says. "I think it's best described in the way Brooklyn smiles every day…how she's a beautiful, vibrant, outspoken 3½ -year-old. And the way she's so full of life." ●

PHOTOS BY SETH DIXON

BrAve HeArt

By Summer Freeman

With a gentle strength and a warrior's resolve, Timothy Parks battles the enemy within.

AT 6 FEET, 4 INCHES, the fighter cuts an imposing figure. Long and lean, he easily stands a head taller than most people. The challenger he faces today, however, is not like most. Ferocious, unpredictable and relentless, the opponent's name alone strikes fear in many.

But our fighter is not discouraged. His resolve is too great and the victory too important.

As any seasoned prizefighter will tell you, it's not the size of the man in a fight that determines the winner; it's the size of the fight in the man.

Those who know Timothy Parks would say their money is on him.

As a teenager, Timothy beat cancer; now, with a relapse at age 20, he's determined to conquer it again.

A born winner

From his first breath, Timothy was a fighter. Arriving two months too early and weighing only 3 pounds, the newborn suffered a brain hemorrhage that held the threat of death or mental debilitation.

"The doctors said all of these devastating things could happen, and with the bleed as bad as it was, we thought we could lose him," recalls Timothy's mom, Theresa. "But he was a fighter even then."

The preemie exceeded even doctors' expectations. "At his check-ups, he was always four to five months ahead in his development," Theresa says. "He walked at 9 months and ran at 12. He talked in sentences very early and could carry on conversations."

Timothy had won.

Show no weakness

By senior year in high school, Timothy was a focused student and dutiful son. An honor roll student, he skipped a grade and was scheduled to graduate a year early, at 16. He was active in the school's Junior ROTC, drill team and color guard programs and held college scholarships—and even an invitation from the U.S. Military Academy. By all accounts, Timothy was an overachiever.

"Bullheaded," Theresa says teasingly of her son's determination. "Tell him there is something he can't do, and watch him prove you wrong."

It is perhaps that same stubbornness that led Timothy to hide the fact that he was becoming sick.

"He was throwing up everything he ate, but he was keeping it secret because he didn't want to miss school," Theresa remembers. "He started losing weight and was always tired. He'd come in from school and go straight to sleep."

The headaches, nausea and fatigue grew worse.

On a Friday in January 2004, Timothy's school called. He was too ill to stay in class and certainly not well enough to drive home alone. A doctor in the emergency room diagnosed the sickness as migraines, caused by stress, and Timothy was given a prescription to curb the headaches.

Timothy took the medicine, but his condition worsened over the weekend. "He started stumbling, and his balance was off," Theresa says. "We knew that something was very wrong."

On Monday, Timothy underwent a CT scan. Before the family returned home from the doctor's office, a call on Theresa's cell phone asked them to come back to discuss the results. Timothy had medulloblastoma, a tumor that arises in the posterior fossa—the lower, rear region of the brain. "I couldn't believe it," Theresa says. "I kept thinking, 'He's not sick enough for something as serious as a brain tumor.'"

Immediately, Timothy underwent surgery at a local hospital and was referred to St. Jude Children's Research Hospital for treatment.

Battle for independence

The surgery to remove the tumor was successful, and Theresa recalls that Timothy was especially upbeat in recovery. "He was talking, and he wanted to eat," she says. "It was like he hadn't just undergone major surgery."

Seemingly, the hard part was over, and the family turned their thoughts to leaving for St. Jude. But on the third day after the surgery, Timothy's world changed.

"He woke up screaming bloody murder," Theresa remembers. "He couldn't talk; he couldn't walk; he

couldn't do anything."

Timothy had developed posterior fossa syndrome, a postoperative disorder that can cause mutism or speech disturbances, decreased motor skills and cranial nerve palsies. Onset typically occurs within 72 hours of surgery, and the syndrome's cause is unknown. Up to 25 percent of patients who undergo surgeries like Timothy's develop the condition.

"We can't pinpoint why some children get it, and some children don't," says Amar Gajjar, MD, co-leader of the St. Jude Neurobiology and Brain Tumor Program and co-chair of the Oncology department. "It is hard for parents to see their normally functioning child behave like that. But it's not like the child doesn't understand what is going on. The child is still very much aware of what is happening."

Timothy describes the feeling as being trapped. "I knew what I wanted to do and say because my thoughts were still there, but all I could do was scream," he recalls.

For the teenager, who excelled so easily, existence became an uncontrollable state of flux. "Before my diagnosis, I was at that point of independence—when you first get your driver's license and are starting to think about life outside of your parents," Timothy says. "But with the posterior fossa syndrome, suddenly I was depending on my parents for everything. They had to feed me, bathe me and push me around in the wheelchair."

Social worker Jeanette Lavecchia met Timothy within his first few days at St. Jude. "He had truly been thrown a curve," she says. "Having been such a goal-oriented high achiever, it was extremely difficult for him."

Heart of a champion

Timothy may have been knocked down, but he was determined it wouldn't be for long.

While undergoing radiation and chemotherapy treatments to beat cancer, he set out to overcome the side effects of the syndrome.

Timothy Parks and his physician, Amar Gajjar, MD.

"He had all the therapies—speech, occupational, physical," Theresa recalls. "He didn't dwell on it; he just started moving forward."

The one or two words he could muster eventually grew to sentences and finally to fluid conversations. He traded the wheelchair for a walker and ultimately for a cane.

"He even grew two inches taller while he was on chemo," Theresa says with a laugh.

Three months after coming to St. Jude, the family was able to return home temporarily for Timothy's high school graduation. Theresa calls it the moment of triumph. "He had his cane with him when we left the house, but when he crossed the stage, he didn't have it. He walked through his whole graduation without picking it up once."

Timothy had won.

Warrior's spirit

In spring 2005, doctors gave Timothy an 85 percent chance that the cancer would not recur, and he was well enough to start college, requiring only return visits to St. Jude every three months.

Timothy enrolled in classes, adopting an 80-mile daily roundtrip commute and the maximum course load per semester. Within 15 months—and while maintaining exemplary grades—he earned an associate's degree in psychology. Not one to settle, Timothy enrolled in another university to work on a bachelor's degree. By 19, he was a second-semester junior with a 3.8 grade point average.

"Despite his illness, he has gone back to college, and he's taking 18 hours of credit or more a semester," Gajjar says. "He's finished the course work and the time he lost initially, but he sets academic goals for himself, and he's determined to meet them."

Theresa laughs. "Dr. Gajjar will tell him not to take so many classes, to slow down. I'll get on him, but when Timmy wants to do something, there is no stopping him."

Timothy's perseverance, Theresa says, has been a source of strength for the family even in the bleakest times. It is also what gave a sense of perspective during a recent trip to St. Jude, when they received ominous news. Timothy did not feel sick prior to the visit, and the January 2007 checkup was supposed to be nothing more than routine. Exactly three years to the day of Timothy's original medulloblastoma diagnosis, two cancerous spots were found on his spine, signaling a relapse.

"It was bad déjà vu," Theresa says. "Of course, I was in shock, but Timothy just looked at Dr. Gajjar and asked, 'OK, what do we do to beat it again?' And I just thought, 'Yes, that's the way we have to look at it. We are going to beat it again.'"

For a fight as big as Timothy is waging, Theresa is comforted that the family is in expert hands. "Before coming to St. Jude, I thought, 'This is a children's cancer hospital; this will be the saddest place I'll ever be.' But then you see the happiness and the hope, and know you're in the best place you could possibly be. I know Dr. Gajjar and everyone is going to do what it takes."

Timothy was given the option to finish his semester before beginning radiation. He opted to withdraw from school and start treatment immediately because college, Timothy says, will still be there after he has defeated cancer. Eventually, he plans on earning a master's degree and doctorate in psychology and then returning to St. Jude to work as a counselor.

"A lot of people think the word cancer is a synonym for death or the end, and it really isn't," he says. "I had cancer before, and I beat it, and now I just have to do it again." ●

By Carrie L. Strehlau

Germ Warfare

PHOTOS BY ANN-MARGARET HEDGES

St. Jude Infection Control is the first line of defense for patients' fragile immune systems.

Infection Control Director Bonnie Williams examines a filter for the purification system that circulates air in the Patient Care Center. Williams and her colleagues are fanatics when it comes to cleanliness—and that dedication pays off in an amazingly low infection rate for St. Jude.

Germs are gross and sneaky. They can worm their way into the body and cause stomach aches, coughing, sneezing and infections. For healthy people, grabbing medicine at the corner store, taking pills for five days, using three boxes of tissues and getting plenty of rest is usually adequate, thanks to the body's immune system—ready to fight invading germs on the spot.

But, when a person undergoes treatment for a catastrophic disease, chemotherapy and radiation can disable the immune system; the immune system's soldiers are not as ready for combat against something as simple as the common cold. For the childrenat St. Jude Children's Research Hospital, germs are a devastating enemy.

Armed for battle

When children cannot fight the germs themselves, St. Jude has its own army of dedicated staff who are ready to fight. From conscientious doctors and nurses who constantly wash their hands to Infection Control staff who spend hours educating construction workers about the dangers of drywall particles to Child Life staff who monitor patient activities for any hint of infection issues, infection control is a No. 1 priority.

"We think about infection control as being central to everything that goes on in the hospital," says Jon McCullers, MD, Infectious Diseases, and coordinator of the infection control committee at St. Jude. "At a normal hospital, infection control is vitally important to keep patients from getting complications. At St. Jude, though, every child is at high risk for getting infections. The cancer protocols do not work if all of the patients are getting infections and not making it. Our job is to have a global view of the institution, to understand what risks threaten our patients and to monitor the kids closely to stop or prevent infections."

> FOR THE CHILDREN AT ST. JUDE, GERMS ARE A DEVASTATING ENEMY.

McCullers is in charge of monitoring and maintaining infection trends within St. Jude.

"When we do find issues or some type of outbreak, it's my job to investigate it," he says. "Also, it is my job to act as the point person for staff to call if there are any questions or problems within the hospital."

Flushing out the enemy

For more than 30 years, Infection Control Director Bonnie Williams has worked at St. Jude and kept a close eye on germs, bacteria and infections that might make their way through the hospital doors or arise after a patient is admitted.

"When there is a specific need, our staff step in and help determine what might be causing infection often by culturing things," Williams says.

For example, St. Jude has specific rules about items like stuffed animals, corrugated cardboard boxes and fingernail polish.

"Some people might think we are ridiculous, but we would much rather be careful," she adds. Williams is also a member of the Patient Special Events Committee and provides guidance to those who wish to bring activities like arts and crafts to the patients.

"A few years ago, some staff wanted to bring dogs into the hospital for pet therapy," McCullers recalls. "We researched the risks, met with staff and created a solution that would provide this type of therapy for our patients but not at the risk of their health. Each week, the dogs are in a specific area away from patient care. The animals must be clean, and patients must have permission from their doctors to participate. Plus, we monitor the activity closely. If we see any bacteria in the kids that we would normally see in dogs, we have to reconsider it."

Rallying the troops

Another important aspect of the job is talking to nurses, researchers, staff and even construction workers on campus about being aware of their surroundings as it pertains to maintaining an infection-free environment.

This is important, Williams explains, because things like construction projects that are considered commonplace at most hospitals can present a mine field of hazards to St. Jude patients. For instance, workers must be careful to avoid the release of aspergillus spores; if inhaled, these fungal spores can later germinate and grow in the respiratory tract.

"When you see our patients wearing masks, it is to protect them from aspergillus spores," Williams says. "Drywall, ceiling tiles—they all contain these spores. Healthy people breathe them in all the time, but we have immune systems to handle it. Our patients do not. So, we have machines that clean the air. We require extra walls in between construction and patient areas. Our air is about 99 percent clean, but we still want to take every precaution when there is any construction in the vicinity."

The Patient Care Center at St. Jude has a purification system that continuously circulates air. Infection Control staff offer input into building design to make sure nothing is done to compromise patient health.

"I think that really speaks to the commitment of the institution to make infection control a top priority," McCullers says.

According to John Curran, director of Design and Construction, the hospital also controls the air pressure in each building and has eliminated carpet in the patient care areas.

"Everything is HEPA-filtered in these areas," Curran says. "We also test this air with particle counts, and it is amazingly clean."

On guard

Like an army always prepared for battle, Infection Control staff conduct whole-house surveillance each month throughout the hospital.

"We really do more than the average hospital when it comes to surveillance," Williams says. "We follow every patient admitted to St. Jude. If they come in with infections or develop them in the hospital, we document it."

Extensive records are kept, trends are monitored and, if a pattern is spotted, action is taken. Last year marked a continuation of low rates for infections acquired at St. Jude. The rate of infections per 100 discharges has gradually decreased from a low of 1.93 in 2004 to 1.91 in 2006, representing the lowest rates in more than 20 years for St. Jude. These rates are also benchmarked against averages from other hospitals in the United States.

"The national averages consist of hospitals that have a very small subset of patients who are immune compromised," McCullers says. "Generally at those big hospitals, the highest-risk patients are ones who have cancer. Those patients tend to have a 10- to 100-fold higher risk of getting hospital-acquired infections than their other patients. We actually have a lower infection rate than normal hospitals have for their general population and an even lower rate compared to a normal hospital's immune-compromised patients."

Williams attributes the low rates to several factors.

"We have progressed tremendously since I started at St. Jude," she says. "The antibiotics we administer have improved—and the way we often prevent an infection before it starts is much more effective. All of these are vital improvements that help us control infection in such a high-risk environment."

Battle cry

If the war against infection had a battle cry, it would be "wash your hands." According to the Centers for Disease Control, devotion to hand hygiene has been shown to stop outbreaks in health care facilities, reduce transmission of antimicrobial resistant organisms and reduce overall infection rates.

"We actually have a lower infection rate than normal hospitals have for their general population and an even lower rate compared to a normal hospital's immune-compromised patients," says Jon McCullers, MD.

"No matter what else people do, hand hygiene is the most important thing you can do to stop the spread of infection," Williams says. "If a health care worker went from patient to patient without washing his hands, imagine how many things could be spread. With our patients, we must constantly wash our hands."

The hospital has sinks outside inpatient rooms and hand sanitizer bottles throughout patient care areas.

"Unfortunately, the frequency of someone washing their hands before entering a patient's room is lower when they have to walk a bit further to do it," Williams says. "That is partly why it was important for us to put a sink near our patient rooms. Believe me, if a family has not heard that sink, they do ask when someone enters the room."

McCullers echoes the sentiment.

"I am a big advocate for empowering the patient's parents to be in charge of protecting their kids and enforcing infection control," he says.

Through creative hospital videos and one-on-one discussions, patients and families are educated about the importance of hand hygiene.

"Once, during a visit from a hospital surveyor, a patient's parent was asked if our staff talked to them about hand washing," Williams says. "The parent looked at the surveyor and said, 'Yes, all of the time.' I believe one of the main reasons we have such low infection rates is because our employees are so conscientious about hand hygiene. Our patients' health is the ultimate motivator."

McCullers says he believes St. Jude is on the forefront of infection control.

"We are small and strict about what we do, so we can more easily manage everything and enforce policies," he says. "We serve a special population at St. Jude, and it is critically important that we be good at infection control or we can't accomplish our mission." ●

Gold in Those Hills

St. Jude leads the way in the rush to harness the human genome and save lives.

By Elizabeth Jane Walker

In January 1848, a construction worker in Northern California spied a lone gold nugget glinting at the bottom of a stream. As news of his discovery spread, thousands of prospectors boarded sailing ships and hitched mules to wagons, converging on the region in a furious race for riches. That tiny fleck of gold transformed the American West.

One hundred fifty-nine years later, a discovery in Memphis, Tennessee, promises to have a similar effect on the field of cancer research. A team of researchers found new mutations that contribute to acute lymphoblastic leukemia (ALL), the most common type of childhood cancer. The strategy the scientists used to make that discovery has started a "gold rush" worldwide, because it shows researchers how they can identify unsuspected mutations in adult cancers, as well.

PHOTOS BY PETER BARTA

Prospecting for a cure

During the past four decades, researchers at St. Jude Children's Research Hospital have made incredible progress in eradicating such childhood killers as ALL. Researchers and clinicians have worked in tandem to figure out how to fine-tune drug combinations and understand the genetic lesions or abnormalities that spawn leukemia. As a result, the ALL survival rate has skyrocketed from a terrifying 4 percent in 1962 to about 94 percent today. While that improvement is reason for celebration, the survival rate is not high enough. The ultimate goal? One hundred percent.

A pathologist by training, James Downing, MD, has spent the past 20 years trying to understand how genetic lesions can cause a cell to become leukemic and how that information can be used to improve diagnosis and treatment. Downing is particularly interested in how that process occurs and how it contributes to leukemia.

"We thought that if we could better understand how each of the genetic lesions leads to leukemia, we could figure out which ones are going to be the Achilles heels that we could develop more specific therapy against," explains Downing, the hospital's scientific director.

Although researchers worldwide have studied the issue, nobody knows all of the genetic changes that lead to leukemia. If scientists could find those genetic lesions and catalog the important ones, new treatments could be created and more lives could be saved.

Until recently, scientists lacked the tools for such a project. Then the human genome project provided a kind of blueprint of what normal genes look like in humans. Scientists also developed new technology to aid in the search.

In 2005, the timing and conditions were right for St. Jude to conduct a study to pinpoint the lesions that lead to leukemia. The hospital had the technology and a vast store of leukemia samples from St. Jude patients. "We thought that we could apply that technology and gain insights into the lesions that were present in leukemic cells that were not present in patients' normal cells," Downing explains. "We would then be able to take that information and start identifying the number of lesions in existence."

Tapping the resources

It was an ambitious proposal, but St. Jude never balks at a challenge. The study would be the largest of its kind thus far. Thanks to the hospital's Hartwell Center for Bioinformatics and Biotechnology, researchers would be able to conduct a gene-by-gene comparison of DNA taken from both leukemic and normal cells.

The team used postage-stamp–sized chips, called microarrays, which contain hundreds of thousands of DNA probes. Using computers, investigators can figure out whether a gene is missing part of its DNA or identify increases in the number of specific genes.

"Nobody else was positioned to do this study," Downing says. "Nobody else had the collection of tumor samples readily available; nobody else had the well-annotated samples where we know the clinical outcome and many other features of the molecular pathology of the leukemia."

Nay-sayers along the way

Not everyone in the scientific community had confidence in St. Jude and its approach to the problem. Opinions were divided. Many scientists believed that there were so many lesions that St. Jude would never be able to identify them, and that the project would be a colossal waste of time. Other people thought the study would not turn up any lesions.

"We were convinced that there were going to be interesting lesions," Downing says. "We knew that it was going to take a lot of hard work and a lot of thought and a lot of well-designed studies to figure out which ones contribute and which ones don't, but we were in a position to do that.

"We are positioned to do it because of who we are—we are St. Jude Children's Research Hospital," he says. "First we had the samples, which are well-annotated and well-stored. But even more importantly, we had the human and capital resources. We have the Hartwell Center for Biotechnology and Bioinformatics. We have Biostatistics. We have a Hematopoietic Malignancy Program that is a team of people who can collaborate on a project like this. And we have the Pharmaceutical Sciences department that

In their quest to find the genetic lesions that lead to leukemia, researchers acquired nearly a half-billion data points from patient tissue samples. The team included (from left) postdoctoral fellows Salil Goorha, MD, and Charles Mullighan, MD, PhD; graduate student Chris Miller; and postdoctoral fellow Ina Radtke, PhD.

has, through years of effort, acquired normal samples on every patient."

And so the project began.

Panning for data

In the following months, researchers acquired nearly a half-billion data points from samples that had been obtained from 242 patients and stored in the hospital's tumor banks.

"That was an unthinkable amount of data," Downing says. "A year before that, a couple of hundred thousand data points would have been a lot. But now we were gathering more than 1.2 million data points on every patient, and we were looking at 242 patients, with many repeated tests."

Nobody—not even the companies that developed the chips—had fully figured out how to analyze all that data.

St. Jude Scientific Director James Downing, MD, headed a study that shows researchers worldwide how to identify unsuspected mutations in pediatric and adult cancers. "To some extent, it's like the gold rush," Downing says. "From a scientific point of view, what this says is that there's gold in those hills. Now we know how to find it, and let's go find it."

No one in the world could tell St. Jude how to combine data from the chips, analyze it, normalize it or visualize it. No one had yet figured out how to develop a program that would statistically pick out likely lesions from the millions of data points on every patient. So teams across St. Jude worked together on the problem.

"Every refinement in analyzing the data helped us see more within it, and so very quickly we were able to show that the data was exquisitely sensitive, highly reproducible and was able to identify many of the lesions that we knew existed," Downing says.

A glimmer of gold

Then the team found a new lesion on one chromosome. "It was a deletion of a gene, and that gene didn't mean anything to us. There are 20,000 genes, so it was just one of the 20,000," Downing says.

On closer scrutiny, the investigators realized that the gene, called *EBF*, was required for a normal B lymphocyte to mature into a mature B-cell. B lymphocytes are the cells from which acute lymphoblastic leukemia arises. The researchers knew that about 100 genes control B-cell differentiation. So they decided to look at all of those genes.

The next gene they looked at was a gene called *PAX5*.

When Downing walked into his lab one day, postdoctoral fellow Charles Mullighan, MD, PhD, was staring at his computer screen, transfixed. "He was literally white," Downing recalls.

"You are not going to believe what I just found," Mullighan said. "Thirty percent of childhood B-lineage ALL have a deletion in *PAX5*."

Nobody had seen that before. Eventually, the team discovered that 40 percent of patients with ALL had deletions or mutations in either *PAX5*, *EBF* or *Ikaros*, three genes that control the differentiation of blood stem cells into mature B cells. When these cells do not mature, leukemic cells continue to grow, eventually killing the patient.

Researchers are now considering ways to develop therapy based on this information, a task that St. Jude is poised to do through its new Chemical Biology and Therapeutics department.

The rush is on

This study showed the world that undiscovered lesions most likely exist for all cancers. And St. Jude showed the medical community how to find them. "So part of the excitement in the field is, 'Wow! There are lesions we don't know about, and here is the way to find them, and everybody should roll up their sleeves and do it,'" Downing says.

"The other part is that this is the first big paper to say, 'There are all kinds of lesions; here's the way to validate them, here's the way to think about them, and here are some tricks to analyze the data. Eventually there is even going to be better technology, but those will just be refinements, and here is the way to go forward.' It shows us where to look so that we can begin investigating new therapies."

Developing therapies based on these discoveries will be a long process. "But, really, to some extent, it's like the gold rush," Downing says. "From a scientific point of view, what this says is that there's gold in those hills. Now we know how to find it, and let's go find it."

Downing predicts that within the next few years, this kind of study will be conducted on every human tumor.

"As a result, an incredible amount of information is going to come out that will be a leap in our understanding of what causes cancer," he says. "People are racing to do this, and that's good. The competition will accelerate research, and we will end up getting answers much more quickly, which is what we are really after, especially in a place like St. Jude. We really don't care about getting the credit; we just want to figure out how to improve treatment for kids with cancer." ●

Life COACH

An athlete turned philosopher shares inspiring life lessons from the school of baseball.

By Ruth Ann Hensley

COURTESY OF SNELL PROSTHETIC AND ORTHOTIC LABORATORY, ARKANSAS

He can tell you the number of stitches in a regulation baseball, Babe Ruth's batting average and the first year the Atlanta Braves won the pennant. He knows the average speed of Cy Young's fast ball, the distance from home plate to first base and the exact date the lower portion of his left leg was amputated. Thirty-five-year-old Robert Byrd learned at an early age that like a baseball, life can come at you fast and hard. When a cancer diagnosis threw him a curve as a promising 11-year-old athlete, he swung back.

Byrd has taken the competitive spirit and drive that made him a sports phenomenon in grade school and applied it to his pursuit of life. His refusal to accept defeat has also inspired kids on the Little League team he coaches to keep swinging, no matter what.

Three strikes

"A log in the trail hit me on the side of the leg," Robert recalls of the minor injury he incurred 24 years ago that would lead to a devastating discovery. "I was riding four-wheelers with my friends, and the log hit me in the left leg." That was the first strike.

A swollen knot formed below his left knee. The tender whelp persisted, and the all star began limping.

A physician in the Byrds' Arkansas hometown referred Robert to a clinic in Memphis. X-rays revealed an aggressive form of osteosarcoma, bone cancer, attacking Robert's femur. That was strike two.

"When you're a boy that age, you think about two things—playing with your friends and playing sports," Robert explains. "When the doctors said I had cancer I thought, 'Okay, what does that mean?' I just wanted to be with my friends and play ball. That's all I wanted to do."

The clinic immediately sent Robert to St. Jude Children's Research Hospital. In a whirlwind three-week period, Robert's aspirations went from reaching home plate to reaching his 12th birthday. Acting quickly to stop the spreading cancer, doctors ordered an amputation of Robert's left leg, 2 inches above the knee. Strike three.

"Robert was so determined to play baseball one more season after he finished chemotherapy that the baseball association let him play," says Opal Byrd of her son, pictured here barely more than a year after his surgery.

"It was May 7, 1984," Robert says matter-of-factly. "My leg was amputated on a Monday. I was released that Friday, and I went home and rode my four-wheeler."

Clearly, three strikes were not taking this slugger out of the game.

A new game plan

"All my brain could think of then was, 'How quickly can I return to normalcy?'" Robert says.

"Amputation was all we had to offer in those days," says Debbie Crom, RN, PhD, a St. Jude nurse practitioner assigned to Robert's case. "He was already being scouted by high school athletic programs because he was so talented, and to walk in that room and tell such a good kid and gifted athlete that we had to remove part of his leg…" Crom pauses briefly, struck by the clarity of that memory. "It's a moving experience that stays with you for a long time," she confides. "But Robert and his family never missed a beat. They focused on getting through this and getting Robert well."

Crom, who later asked Robert to speak to other patients undergoing amputation, credits Robert's parents for his positive resolve. "He reflected the attitude of his mother and father—that he could do anything without a leg that he could do with one," she says. "They had a strong, underlying faith that charted the course for their son."

Robert, who was fitted with his first prosthetic limb six months after surgery, agrees. "Through the entire ordeal, my parents were always there. They encouraged me and inspired me to never give up," he says. "They taught me that if you want something in life, you have to work for it. You can't rely on someone else to do the job for you."

Winning drive

Those lessons rang true when Robert had to undergo a 42-week chemotherapy program, in the days before effective anti-nausea drugs were available; and a second surgery, a year after the first, to remove a bone spur at the base of his amputated limb.

Even someone whose personal motto is, "Thank you, dear Lord, for letting me wake up, and I will deal with whatever happens this day," faces moments when that is not easy.

"I remember a couple of days before my surgery, just looking down at my leg and kind of crying. I told my leg, 'Goodbye. I'm not ever going to see you again.'" Robert recalls. "That was very, very hard for me—knowing a part of your body is really gone."

The future as Robert once saw it was also gone. "I excelled in every imaginable sport, and I don't mean that in a bragging way," he explains. "Sports were the pinnacle of my life back then. My future as an athlete was bright; what it may have held I don't know, but suddenly it was taken away from me."

But as fast as a homerun can shake a batter's slump, Robert kicks the dust off his shoes and shifts into coaching mode… sharing life lessons.

"I learned not to pity what I had lost, but to take that motivation, that drive that I had in sports, and use it in other areas of my life," he says. "So when we talk about purpose in life and why things happen, maybe that is part of it."

Perhaps another part of it is inspiring the Little League baseball players on the team he coaches, a team he refers to with a father's pride as the cream of the crop.

"These are 8-year-old kids, but if you use the tool right, you are giving these children valuable life lessons," he says. "I try to teach them how to take the game of baseball and apply it to life. I tell them, 'If you strike out, you have to get back up; you have to try again."

Crossing home

When he's not coaching Little League or working as a senior marketing analyst for a communications company in Arkansas, Robert pursues his passion for photography and spends time with his wife and stepson.

Since the early 1990s, limb salvage procedures have greatly reduced the number of amputations for patients like Robert. However Crom, who now works as a nurse practitioner in the St. Jude After Completion of Therapy Clinic, explains that even a long-term cancer survivor like Robert is not entirely out of the woods.

"Issues like heart disease, nerve damage and infertility can affect these patients later in life due to the toxicity of the treatments," Crom says. "That's why the studies we conduct with our survivors are so important, as we continue to develop safer, targeted therapies."

But Robert was glad he was *in* the woods that day riding his four-wheeler when what he calls a "miraculous log" hit him in precisely the spot where his cancer was growing.

"I know someone was watching over me that day," Robert says. "Something caused that log to hit me. Then the doctors found the cancer and did what they had to do about it—and here I am today."

With his inspiring drive and determination, Robert has racked up some impressive stats of his own. He achieved an unheard of .569 batting average when he returned to the baseball diamond a year after his surgery, wearing his prosthetic limb. He has coached Little League for 16 years and has seen the legendary baseball film *Field of Dreams* 12 times. But it is Robert's winning attitude in the game of life that has scored the biggest hit with friends, family and enough 8-year-olds to fill a triple-A ballpark. It's one for the record books. ●

PHOTO BY SETH DIXON

Perspective

It's All about the Children

"Adults have lived their lives, and children haven't. I want to help give kids the opportunity that we've been given. As adults, it's our duty to give back to kids and to do what we can to help them live long, healthy lives."

By Jaime Pressly

For the past several years, I've helped raise money for a place I've never visited and for children I've never even met. Some people might think that's unusual, but I think it makes perfect sense.

The place is St. Jude Children's Research Hospital. I've tried to visit the hospital several times, but a conflict has always come up at the last minute with my work that prevents me from making the trip. But that doesn't really matter. You see, I don't think you have to go to St. Jude to want to help. For me, it's about being enthusiastic about helping children. That's what the hospital is there for—to help kids. I think if you love children as much as I do, then you do whatever you can do to help them.

My involvement with St. Jude began several years ago when I joined Coors Light in a Halloween fundraiser during the month of October. All of the proceeds from that project went to St. Jude. We raised more than $2 million in one month just through that campaign alone. That was pretty great. And that's when I rolled up my sleeves and began doing what I could to support St. Jude.

I'm somebody who likes to see how much more I can do—in a big way. So I've been helping ever since.

PHOTO COURTESY OF WIRE IMAGE

Last October, we had a fashion show for my J'aime line of clothing. At an after-party, we raised about $15,000 in three hours. And recently, as part of my baby shower, Godiva donated $25,000 to St. Jude. I'm expecting a baby boy about a month from now.

I think it's important to support St. Jude because of the amazing things that they do for children and their families. They're a charitable organization that doesn't ask for a dime from the people who really need their help.

Adults have lived their lives, and children haven't. I want to help give kids the opportunities that we've been given. That's why I do all the fundraisers I can for children. As adults, I think it's our duty to give back to kids and to do what we can to help them live long, healthy lives.

The things St. Jude does amazes me. The organization has to raise millions of dollars every year so that it can continue saving the lives of kids. As an actress—and as a mom—I need to do everything I can do to make that possible.

You never know, it could be your child—God forbid—who needs their help.

Emmy-award nominated actress, model and fashion designer Jaime Pressly is the star of the NBC sitcom My Name Is Earl, *has appeared in numerous movies and has her own clothing line, J'Aime.* ●

Cinderella has nothing on St. Jude patients. The hospital held a prom for patients and siblings this spring in the Danny Thomas/ALSAC Pavilion. Dresses were donated by hospital employees. The Child Life department coordinated the dance and arranged for outside salon specialists to assist the girls with their hair and make-up. Glass slippers were optional.

PETER BARTA

St. Jude Children's Research Hospital
ALSAC • Danny Thomas, Founder

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