

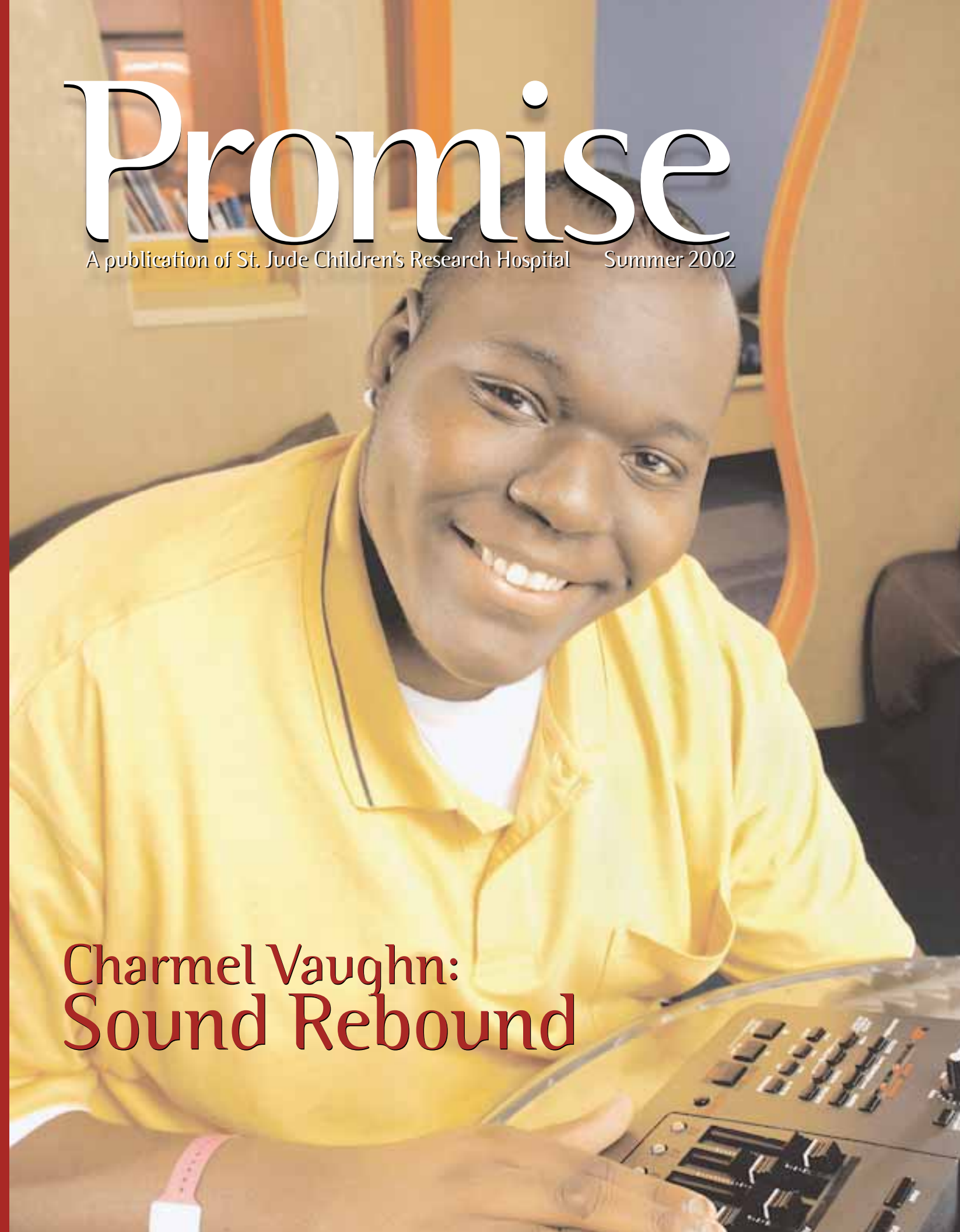
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Promise

A publication of St. Jude Children's Research Hospital Summer 2002



Charmel Vaughn: Sound Rebound



St. Jude Children's
Research Hospital

ALSAC • Danny Thomas, Founder

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

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

Promise.



St. Jude Children's Research Hospital, Memphis, Tennessee

Promise

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St. Jude Children's Research Hospital's mission is to find cures for children with catastrophic diseases through research and treatment.

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Features

3 Click.

Donor Howard Jones

4 Sound Rebound

Christian rapper Charmel Vaughn

9 Cooking Up a Fund-Raiser

Two decades of bake sales



10 Tailoring Treatment

A revolutionary genetic screening technique



15 In Their Own Words

St. Jude poets



19 Less Pain, More Gain

Pain management at St. Jude

Highlights

2 Day of Remembrance Research Highlights

Perspective

24 Daphne Dawn Harrison Terral

A survivor for nearly four decades

Promise is now available on the Internet!
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St. Jude Children's Research Hospital is an equal-opportunity employer. For inquiries about stories in this publication, call the Public Relations department at (901) 495-3306 or e-mail elizabeth.walker@stjude.org. Visit our Web site at www.stjude.org/Promise. Articles and photos may be reprinted with permission. ©2002. On the cover: St. Jude patient Charmel Vaughn. Photo by Seth Dixon.

Highlights



St. Jude parents who have lost children during the past two years release butterfly balloons during Day of Remembrance in April. More than 160 people attended the fourth annual event. Families and staff members reflected on their experiences together, in activities designed to foster healing and closure in the grief process.

The gene scene

St. Jude scientists have identified a defective gene that may help doctors better understand some neurological diseases and treat nerve-degenerating accidents.

“The discovery could shed light on the pathology of neurological diseases such as Alzheimer’s disease, Parkinson’s disease and retinitis pigmentosa (a degenerative eye disease),” says Jian Zuo, PhD, of St. Jude Developmental Neurobiology. Researchers also found an unexpected link between nerve degeneration and regeneration by studying the gene *Nna1*.

The discovery may help doctors who treat nerve-degenerating accidents, such as head injuries and radiation-induced nerve damage. The research, involving four institutions, was published in the March 2002 issue of *Science*.

AML model

A method that enables researchers to study the development of one type of acute myeloid leukemia (AML) in laboratory mice should assist scientists studying cancer in humans.

The study is the first to devise a way of controlling the genetic expression of specific cellular targets. The method involved engineering mice to express a mutated protein considered to be a trigger of AML.

“This model will help us devise better ways to diagnose AML, predict a patient’s chance for being cured using conventional therapy and develop new therapies,” says James Downing, MD, chair of St. Jude Pathology.

The findings were published in the February 2002 edition of *Cancer Cell*.

Children and emotions

Children with cancer and other serious illnesses often adapt to their conditions by repressing their emotions and covering up feelings of depression and anxiety, according to a new study.

Children may block out depression and anxiety symptoms to cope with the practical demands of their illnesses. But by repressing their feelings, children may ignore important warning signs of their illness or their emotional response to it, says Sean Phipps, PhD, of St. Jude Behavioral Medicine.

The study, published in the January 2002 edition of *Psychosomatic Medicine*, will help psychologists deal with children who may not indicate that they are distressed.

Improving treatment

Scientists have found a new way of activating the anti-cancer drug CPT-11. The discovery could lead to more effective treatment for patients using CPT-11, improving therapy of solid-tumor cancers in adults and children.

The study describes the structure of a rabbit liver protein that activates CPT-11. The research, led by Phil Potter, PhD, and Mary Danks, PhD, of St. Jude Molecular Pharmacology, appeared in the May 2002 issue *Nature Structural Biology* and used rabbit proteins purchased from commercial sources.

Click.

One simple act has far-reaching consequences.

BY ALICIA H. MATTHEWS

Sometimes the flip of a switch can affect a person’s life forever. Such a situation occurred nearly 30 years ago, when Howard Jones came home from the office and turned on his TV set.

“My wife and I were watching a television show that featured Danny Thomas talking about St. Jude. It was one of his original promotions where he performed to solicit donors for the hospital,” Jones recalls. “We were so touched by the program that it brought tears to my wife’s eyes.”

That interlude in front of the television transformed the Joneses’ lives; their subsequent donations of time and money in turn have

continued to be supporters through the years,” says Jones, a real estate investor who lives in Santa Ana, California.

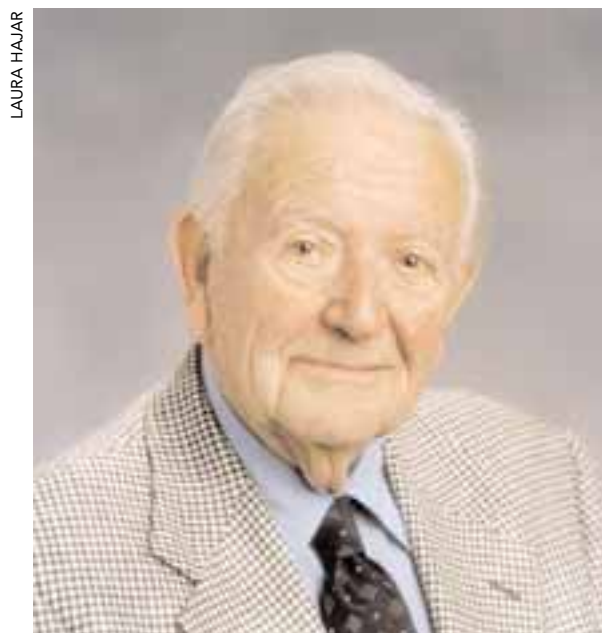
He later met the entertainer when Los Angeles County honored Thomas for his humanitarian work on behalf of children. Because of his prior involvement with St. Jude, Jones felt privileged to participate in the program. “It was so interesting to meet Danny. I could just see his commitment to the kids at St. Jude,” Jones says. “When he came to receive his award, he even brought a pair of shoes with him that represented the children who had walked in the Teenage March for St. Jude. He wanted to salute

have special meaning to Jones because he wrote them.

Some people might not understand why a person who lives in California would support a hospital in Memphis, but Jones understands that St. Jude research findings help children everywhere. That is one reason he has embraced the hospital as one of his most important causes. He and his wife have established a trust that helps provide for the hospital’s current and future needs. Jones has also redoubled his commitment to ALSAC/St. Jude by serving on the Professional Advisory Board, a group of national leaders who provide guidance and support for the institution’s fund-raising efforts. Working alongside other PAB members, Jones helps to generate new ideas that will help propel St. Jude forward for many more decades.

After years of involvement with the hospital, Jones continues to hold a special place in his heart for the children of St. Jude, whose courage never ceases to amaze him. “The kids are so enthusiastic, and the personalization of care provided by the doctors to each child is beyond anything offered at other hospitals,” Jones says. “Because of the vast research being conducted at St. Jude, I feel that if I needed help I could put my grandchildren in the hands of St. Jude and not have to worry.”

The click of a switch. It might just affect the lives of generations to come.●



affected countless children suffering from catastrophic diseases. “We have been sold on the hospital since that first encounter and have

plaque awarded to Thomas by L.A. County hangs in the Danny Thomas/ALSAC Pavilion. The words imprinted on the plaque

One TV program 30 years ago inspired a lifelong commitment to St. Jude. California businessman Howard Jones and his wife have established a trust that helps provide for the hospital’s current and future needs.



PHOTOS BY SETH DIXON

Sound Rebound

ST. JUDE patient
CHARMEL VAUGHN
blends RAP with RELIGION.

BY ELIZABETH JANE WALKER

On a Sunday afternoon in a makeshift production studio, a 19-year-old musician and three lovely backup singers raise their voices in praise. They extol the blessings of grace and the joys of faith. But this ensemble doesn't croon gospel favorites like "Amazing Grace" or "Kum Ba Ya." They perform rap.

Yes, rap—that rhyming, rough-hewn music that pulsates from cars, stereos and boom boxes

across America. Like rock 'n' roll before it, rap's rhythm revolution has infiltrated American culture. In a tidal wave of sound, the pounding beat of rap has begun to wash over the Christian music industry, as well. St. Jude patient Charmel Vaughn is wading hip deep in that sanctified surf.

Music and mortality

Charmel doesn't live in a bustling metropolis like New York

or Los Angeles; he comes from a more bucolic setting—a small town in rural Mississippi. Inside the trim red brick house at the end of a quiet cul-de-sac, the tunes are hot, the tempo is infectious and the lyrics are thought provoking. Today, the members of Saved Untouchable Souljahs—Charmel, his sisters, Chamara and Chenita, and their friend Tonette Coffee—spend the afternoon laughing, dancing and rapping in Charmel's bedroom-cum-production studio.



“Charmel’s always got a smile on his face,” says Heather Haluska of the Child Life Department. Other St. Jude staff members agree that the gifted rapper with the outgoing personality, gentle spirit and perpetual grin has influenced countless patients at the hospital, just by hanging out in the Teen Room and sharing his music.

Near the high-tech recording equipment, an assortment of prescription pill bottles is the only sign that this teen faces challenges beyond the usual pressures of youth.

A beat spirals up, charging the atmosphere with an almost palpable excitement. Bodies begin to sway as Coffee’s rich descant takes wing and soars above Charmel’s deep rap. The instrumentals are sophisticated, the language is hip and the message is deadly serious:

*You never know if you gon’ live or gon’ die,
Steady spreadin’ the word of Jesus
Christ until he piercin’ the sky.
I’m tellin’ my people the end is comin’
man and that ain’t no lie*

You betta get saved, don’t try to resthave tryin’ slowly get by.
You never know...*

Listeners of traditional rap might be surprised that a teen would write such apocalyptic lyrics. But most teen-agers have not contemplated their mortality during a battle with cancer. Charmel has. He wrote this particular riff while undergoing a grueling chemotherapy regimen. For a musician who says he’s “saved and sanctified,” writing “You Never Know” was a natural response to a difficult situation.

In the summer of 2000, Charmel

**Resthave – to prolong*

found a small bump on his leg. The knot grew, in spite of medications prescribed by the family physician. “My doctor said it was probably a benign tumor, and he referred me to another doctor to do surgery,” Charmel recalls. “It was huge by then, bigger than a softball. It was like I had three knees.” When the surgeon realized the tumor was malignant, he referred his patient to St. Jude. Charmel soon learned that he had Ewing sarcoma, a cancer that arises in the bone or soft tissues and rarely occurs in African Americans. He underwent chemotherapy, radiation and an operation to remove the tumor. Then—just when Charmel thought the ordeal was almost over—he slipped and broke his leg. Surgeons repaired the fracture, but the tissue around the area began to die. In March of 2002, he underwent a third operation, this time to replace the dead tissue with healthy muscle and skin tissue.

“He’s doing well now,” observes St. Jude hematologist-oncologist Sheri Spunt, MD. “Soon he should be able to boogie all he wants.”

Attitude adjuster

St. Jude staff members have been amazed by Charmel’s attitude throughout his treatment and setbacks. “He tries to find something good and positive out of every situation,” says Lunetha Britton, RN, who coordinates the hospital’s Surgery Clinic. “A lot of patients his age are very angry because of the disturbance in their lives. But Charmel has always focused on what he needs to do so that he can get where he needs to be. I’ve seen patients who were really depressed until they started hanging out with him. His attitude, his personality and his calmness seem to rub off on them.”

For more than a year, Heather Haluska of the Child Life depart-

ment has watched Charmel interact with his peers. “Charmel’s one of those dynamic people others just enjoy being around,” she says. “He plays his CDs all the time, and the kids love them. They’re inspired by how he has dealt with his situation and by how he’s moving forward to pursue something he feels strongly about.”

St. Jude patient Jamaal Rasberry, 18, forged a relationship with Charmel by hanging out in the hospital’s Teen Room. “He’s a good role model and a great friend,” observes Rasberry. “And I haven’t talked to anyone who doesn’t like his music.”

Jammin’ at St. Jude

Rasberry is not the only person jamming to Charmel’s music. Doctors, nurses, radiation therapists and social workers throughout the hospital are begging the patient for copies of the CD he has created but not yet begun to market. “When I first learned that Charmel was a gospel rapper, I’d

never heard of those two terms coinciding,” says Matthew Krasin, MD, of Radiation Oncology. “At first, I had to listen really hard to understand his music, because he speaks incredibly fast. Now I’m bugging him to give me a copy of his CD before he becomes famous and I have to pay for it!” Britton predicts that she’ll someday be telling Charmel’s fans “I knew him when...”

This music that transcends race, age and gender barriers began to evolve when Charmel was a small boy, composing raps in the living room with his sister. As their skills increased, the duo began to perform in their church. When a popular gospel rap group held a concert and talent quest in Nashville, Tennessee, Charmel and Chenita traveled to the event and entered the contest. They won. “I can’t begin to tell you all the concerts that we’ve done since that time,” muses Charmel.

After writing “You Never Know,” Charmel began composing melodies and beats to accompany

his lyrics. With a beat machine, he creates the tunes and rhythms, blending the sounds with an eight-track recorder and transferring the finished product to a CD. “I do my drums first,” he explains. “Then I can go behind the drums and put a bass line in. After that, I can add some piano or strings or guitar. It’s simple.”

The process may be simple for a person blessed with innate musical ability and technical know-how, but it’s not as elementary as Charmel implies. “He’s very modest,” says his mother, Vernita Mitchell. “He’s been playing the drums at our church since he was in the sixth grade, and he can just go to the keyboard and pick things out. He’s extremely gifted in music.”

A firm foundation

Members of Charmel’s church, Agape World Overcoming Christian Center, prayed for their young drummer as he battled cancer. A week before each of

Charmel’s operations or procedures, the Rev. Doris Day would organize a prayer vigil. The entire congregation would gather for an hour each day to pray for the patient. Twenty-six other “sister churches” also joined the call to prayer. “God has been awesome through it all,” says Mitchell. “I felt so upheld that I have been able to sit in the hospital chapel and pray for other moms that I see here.”

“I trust in the Lord in everything that ever happens to me,” says Charmel. “I think the Lord took care of me through the whole thing. Of course, prayer helped



Chamara Vaughn, Tonette Coffee and Chenita Vaughn join Charmel in his “production studio.” Although Charmel has been writing and performing gospel rap for many years, he became serious about the genre after winning a Nashville, Tennessee, talent contest in 1999. He wrote the lyrics to “You Never Know” while undergoing chemotherapy at St. Jude. Charmel aspires to earn a degree in commercial music and then launch a career as a writer, performer and producer.

me through it. A *lot* of prayer.” Charmel rarely talks about his faith during casual conversation; he prefers to communicate his beliefs through music. And communicate he does—his words flowing effortlessly in a torrent that prompts listeners to ask, “How do your lips move that fast?” and “Why did you decide to do Christian rap?”

Primed for rhyme

Critics of rap music howl that the milieu glorifies profanity, endorses violence and demeans women. Those detractors are correct, in some instances. But is the ethos of rap music morally incompatible with the values of conservative Christianity? Charmel and his mom say no. “‘Amazing Grace’ and ‘Near the Cross’ are not going to move everybody,” says Mitchell. “For my generation, they were good. But this generation is living to the bump-bump, bump-bump-bump of rap.”

“And what’s a better way to reach teens than through rap?” Charmel interjects. “More people are listening to rap than to anything else.” Indeed they are. In 1998, rap became America’s top-selling format, eclipsing country, jazz and rock. But the hottest new genre on the entertainment horizon is Christian music, which enjoyed double-digit growth last year.

Charmel’s compositions blend the *phat** texture of rap with the Gospel message. “We have a distinct sound,” says Coffee. “Everyone can relate to our music.” “We talk about the Lord, but we have fun with it,” adds Chamara. “If you want to get out there and dance with us, that’s OK.” The praise tunes pull listeners in, but

the lyrics force them to think. For instance, in “Breathin’ to Death,” Charmel turns his gentle gaze toward citizens who are complacent and self-satisfied. “We always dwell on the sinners—the drug dealers and all those people,” he says. “But what about the ones who’ve got good jobs and degrees, but are still not living for the Lord?”

*Your fortune and fame
Go all up in flames
All your degrees
Are left in debris.
When it’s all said and done,
You’ll be hitting your knees
Beggin’ and cryin’ and asking God
please...*

Although Charmel plans to pursue a career as a writer and performer, he also wants to produce CDs and recruit other gospel rappers into the fold. “I’m going to go to college and study commercial music and then start up a small,

independent label,” he asserts. “I’m not worried about my tumor coming back; I know it’s not gonna come back.” Focused, optimistic, and ever thankful for his health, Charmel is primed to go forth into the world—creating, performing and producing righteous raps that rock.●

*Although you give him no regard,
You got your health from the Lord,
You got your wealth from the Lord,
It is Jesus Christ that gives you life
He cares for you
Dare to believe it’s true
Surrender to his way,
But if you don’t your life’s in vain.
It’s in vain.*

—Breathin’ to Death

You can listen to Charmel’s song, “You Never Know,” online. Visit the *Promise* magazine Web page at www.stjude.org/Promise.

**Phat* – great; addictive; well put together.



Charmel has served as the drummer at his church, Agape World Overcoming Christian Center, since he was in the sixth grade.

St. Jude saved the life of her son. For the past two decades, Gemma Wupperman has been using her culinary talents to show her gratitude.



Cooking Up a Fund-Raiser

Take two parts elbow grease, one part gratitude and—voilà! You have a series of bake sales that cover two decades and raise thousands of dollars for St. Jude.

It began as a simple bake sale. Today, it has evolved into a full-fledged ethnic extravaganza, a culinary delight for friends and customers, and a special tribute to St. Jude Children’s Research Hospital.

You see, Gemma Wupperman cooks to say “thank you” to St. Jude for saving the life of her son, Eric.

“I wanted to do something to help them out,” she recalls. “I couldn’t do bike-a-thons or golf tournaments or any of those things. The only thing I knew how to do was a bake sale.” The first year, Wupperman made a number of cakes and cookies and other sweets and held a bake sale in her home. That sale raised between \$300 and \$400 for the hospital.

She recently put the finishing touches on her 20th annual bake sale for St. Jude, which raised \$3,000. Wupperman says she is

thrilled to have played a role in helping St. Jude continue the work that saved her son’s life. “I want to help other children the way my child was helped,” she says.

Wupperman and her family arrived at St. Jude only a couple of years after moving to the United States from Trinidad. A doctor told her that her young son had acute lymphoblastic leukemia and that he needed treatment. The family had no friends to speak of and no medical insurance. Then the physician suggested St. Jude as a place where Eric could receive quality treatment. Although the family had never heard of the hospital, they elected to follow the doctor’s advice. “They were wonderful there,” Wupperman says about the St. Jude staff.

Wupperman never dreamed that her bake sale would become a long-standing tradition or that it would experience such growth.

BY JOE HANNA

Following the first year, the sale of sweets was overshadowed by sales of other dishes. Some items, such as *pelau*, a chicken-rice combination, retained the ethnic flavors of her native Trinidad; others, like *aros con pollo*, hailed from South America.

When the fund-raising project outgrew Wupperman’s home, Eric’s school donated its facilities for her use. Gradually the events evolved into what she calls “bring-and-buy” bake sales. People who came to buy the scrumptious food were asked to bring items of their own to replace what they had purchased. Donations ranged from fruit baskets to potted plants: “anything that would sell,” says Wupperman, who still caters to her customers’ demands for variety by baking about 40 different dishes.

Wupperman, who lives in Florida, has decided that it may be time to put the baking aside, but she says she intends to continue volunteering for St. Jude.

And her son? He’s following in his mother’s footsteps. The 27-year-old cancer survivor is a chef in Colorado.●

Tailoring treatment

When it comes to **LEUKEMIA** treatment, **ONE SIZE** does not fit all. A revolutionary **GENETIC SCREENING** technique devised at **ST. JUDE** will allow doctors to tailor treatment with **PINPOINT** accuracy.

BY TANUJA COLETTA

If Chase Coleraine, 12, ruled the world, the Indianapolis Colts would win the Super Bowl, the St. Louis Cardinals would take home the World Series pennant, and the Memphis Grizzlies would sweep the NBA Finals. The happy-go-lucky Tennessean with the charming grin is a sports nut. His summer baseball league schedule has been stuck to the refrigerator since January. If he's not playing basketball or riding his bike, he's swimming or fishing or darting around on his scooter.

So when Chase started coming home from school sluggish and tired, his parents, Jennifer and David Coleraine, got their first hint that something was wrong. Chase began experiencing severe thigh pain and blotchy bruising on his

legs. At first his parents assumed Chase had dived after too many loose basketballs or had taken one too many turns on the Pogo Ball. But after many tense days and dozens of tests, they learned the diagnosis: acute lymphoblastic leukemia (ALL). Chase's father describes the days it took to confirm the diagnosis as a shocking blur. Chase's mother calls the waiting "pure hell."

When they arrived at St. Jude Children's Research Hospital, the Coleraines discovered that Chase had the home-court advantage in the best cancer-fighting arena in the world. Soon after his arrival, the hos-

pital's doctors and researchers unveiled a new gene screening technique that will help future patients avoid the agonizing wait for a diagnosis. The new technique will also allow patients to undergo a more precise, tailored treatment than has been available in the past.

So far, ALL, despite its 80 percent cure rate, has evaded some treatments because doctors have been unable to predict the risk of relapse and because of certain biological aspects of the cancer itself. Now it seems that ALL has met its match with a tiny glass disc called a gene chip.

Great revolutions

Seven years ago, James Downing, MD, gave a presentation that included a single slide mentioning a new method called gene expression profiling. The technique allows researchers to screen thousands of genes at once to reveal a person's genetic fingerprint; the process can determine a patient's risk for relapse or other treatment complications such as second malignancies or infection.

PHOTOS BY EVANNE NEWMAN

At the time Downing made his presentation, researchers across the world were beginning to uncover the technology's vast possibilities. Downing, chair of the St. Jude Pathology department, now heads a team that has published the largest, most comprehensive study of its kind, analyzing the cells from 360 St. Jude ALL patients.

"I think this technology is opening a new door to the way we examine cancer," says Downing, who adds that the study is a preliminary look that will require extensive follow-up. "This is a first step, but it comes during a time in science when great revolutions are taking place," he continues. "It's going to add incredible biologic insights, incredible advances in diagnostics, and likely, incredible advances in therapy."

While the decision to study gene expression as it relates to ALL seems like a no-brainer now, it was not so clear a year ago. "It's a very expensive study, and when we started the study, we knew that there were other people doing similar work," Downing says. The technique is also being tested with other diseases including lung cancer, breast cancer and AIDS. "We critically asked ourselves if doing this study at St. Jude would add value to the general body of leukemia research. Our belief was that answer was a resounding yes."

Large numbers of frozen clinical samples had already been stored in St. Jude tumor banks. The researchers would also have access to clinical information gleaned by the hospital's clinicians, biostatisticians and pathologists. "We have a unique population of samples because we've treated our patients in a uniform way," Downing observes. "We

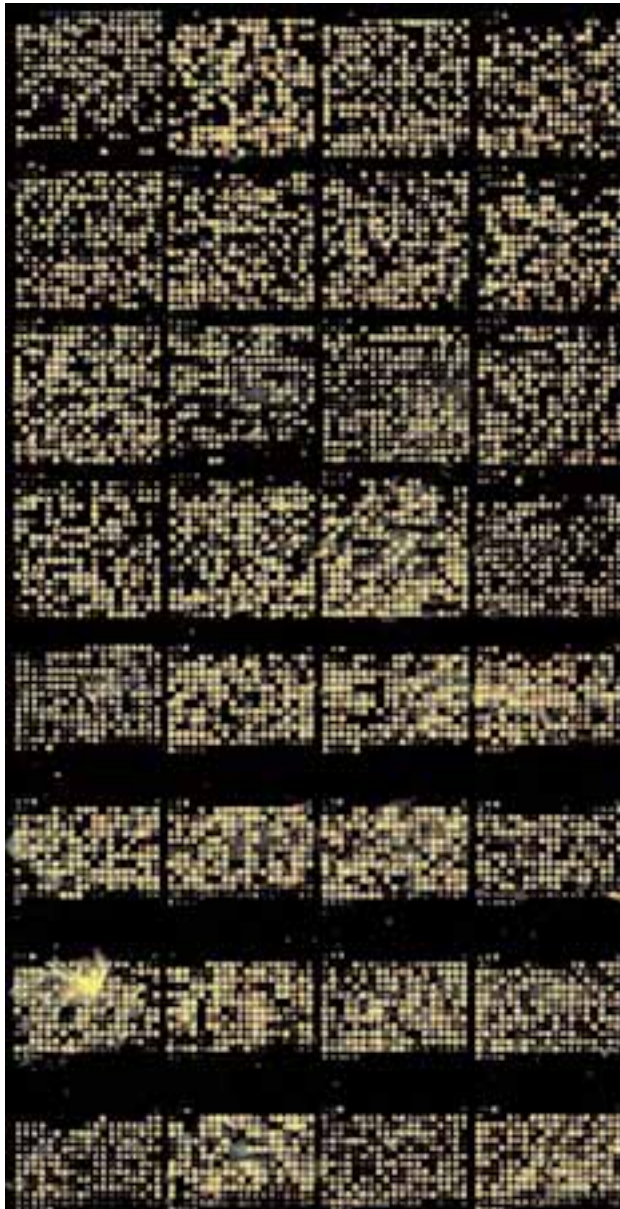


IMAGE COURTESY OF CLAYTON NAEVE

Red means "on" and green means "off" on the gene chip. To find out which genes are turned "on" or "off"—expressed or not expressed—in a cell, molecules representing active genes are extracted, tagged with fluorescent dye and washed over the chip. The expressed genes bind to their counterparts on the chip and are detected by measuring the light given off by each cell on the array using special laser scanners.

also have complete molecular, diagnostic, immunophenotype and cytogenetic data, as well as outcome information. Doing this study would definitely add value for everybody working on adult and pediatric leukemia."

The research team had guessed that gene expression profiling would prove that various ALL

subtypes have different gene expression patterns, but Downing says that the level of distinction surprised the scientists. The technique proved 96 to 100 percent accurate in identifying ALL's six known subtypes and even may have detected a new one. Since each subtype is sensitive to different forms of treatment, the findings will allow doctors to save the most intense therapies for children with the highest-risk leukemia.

Although current ALL treatment is a refined process, tailored to a patient's risk of relapse, the present method of identifying high-risk versus low-risk patients has been difficult and expensive. It can require up to 10 medical experts and about \$1,000-worth of tests from as many as four laboratories. If gene expression profiling proves to be a better identifier, it could replace all

current diagnostic tests while giving investigators much more information than any previous methods have done. The new information can give researchers a broader understanding of a tumor's biology, which in turn could be used to develop new targets for therapy.

"That is an important result,"

Downing says. "It gives us an insight we could never gain before and shows that this kind of expression profiling could be used in a clinical setting with incredible accuracy." He credits the high level of precision to the St. Jude computing powerhouse, the Hartwell Center for Bioinformatics and Biotechnology.

Slam-dunk research

Hartwell Center Director Clayton Naeve, PhD, is certain that gene expression profiling will

help researchers win the game against ALL. "This technology is going to revolutionize medicine," he says. The microarray technology and mega-computing output provided by the Hartwell Center is to St. Jude research what a Shaquille O'Neal slam dunk is for the Lakers. "The Hartwell Center gave us the power to analyze the 4 million pieces of raw data that came out of this study," says Downing. "That is much, much more data than any of us were used to. We knew from the very

beginning that we couldn't do it without the kind of expertise and software the Hartwell Center provided."

The bulk of the analysis took place in the center's Clinical Applications Core Technology lab—also dubbed the Affymetrix lab after the company that manufactures the gene chip. The gene chip—also called a microarray or DNA chip—is a small square glass wafer about the size of a dime, encased in a little black cartridge. Each chip contains an array of



Avowed sports nut Chase Coleraine wears his baseball cap even when he's at the hospital. Earlier this year, the high-spirited youngster, shown with Brenda Steen, RN, endured days of waiting to obtain an initial diagnosis of acute lymphoblastic leukemia. Soon, such a wait may be a thing of the past, thanks to new techniques developed by St. Jude scientists.

several hundred thousand different cells, each containing DNA molecules representing a particular gene. More than 12,000 genes are represented on the chip by these DNA molecules. To find out which genes are turned “on” or “off”—expressed or not expressed—in a cell, molecules representing active genes are extracted, tagged with fluorescent dye and washed over the chip. The expressed genes bind to their counterparts on the chip and are detected by measuring the light given off by each cell on the array using special laser scanners. After investigators perform a massive data analysis, they can use the information to determine whether a person is destined for a good or bad prognosis.

“We are essentially getting a snapshot of a person’s genetic status,” Naeve says. All results are valuable, even if they indicate that a person has little hope of responding to conventional therapy. “Knowing that kind of information can save two to three years of barking up the wrong tree,” Naeve explains. “Instead, we can start looking for new approaches immediately.”

Naeve is confident that gene chip technology will move from the research lab into the hands of doctors within the next three to four years.

Winning the game

By the time the gene chips become a routine diagnostic tool, Chase Coleraine will likely be playing sports again on a regular basis. His doctor, Ching-Hon Pui, MD, is excited about how the technique will affect patients that come after Chase. “This is a big step,” he

says. “It’s going to help in several ways, especially to make accurate diagnoses. Even under the best circumstances, it’s possible to misclassify 2 percent of patients since leukemia sometimes presents itself in unusual ways.” Pui adds that the technique will be less expensive compared to the host of other tools used now; because diagnostic results will come back more quickly, patients will also have shorter hospital stays.

The thousands of genes represented on the chips used in the recent study represent only 30 percent of the entire human genome. Pui is waiting for chips with higher density to arrive

Within the dime-sized Affymetrix gene chip is an array of several hundred thousand different cells, each containing DNA molecules representing a particular gene. More than 12,000 genes are represented on the chip by these DNA molecules.



once the Human Genome Project—the federally funded effort to map out the 30,000 or so genes in human DNA—is complete. Even better would be special ALL or leukemic chips containing just the genes that characterize the disease.

St. Jude will continue studying gene expression profiling, expanding the study to include other rare genetic occurrences with leukemic cells. Through a St. Jude Web site (<http://www.stjude.com>), other researchers worldwide can access the 4 million pieces of raw data in the study’s database and offer their insights on the topic.

Pui agrees with his colleagues that this is a groundbreaking time in science. “This research parallels advances being made throughout the field with the completion of the Human Genome Project, the growth of biotechnology and all the advances in pharmacogenetics,” Pui says. “It’s explosive.”



Clayton Naeve, PhD, director of the St. Jude Hartwell Center for Bioinformatics and Biotechnology, believes gene chip technology will likely move from the research lab into the hands of doctors within the next three to four years.



Ana Duran, age 11

LAURA HALLAR

In 1916, poet Robert Frost wrote, “A poem ... begins as a lump in the throat, a sense of wrong, a homesickness, a lovesickness.... It finds the thought and the thought finds the words.” Some members of the St. Jude family express their deepest thoughts by putting pen to paper or fingers to keyboard. Here, a few of the hospital’s poets share their words with the world.

In
Their Own
Words

My Pencil Case

By Ana Duran

In my pencil case I have a Sharpener to take out all my bad Memories from my head:

An eraser to erase all my sins,
A ruler to be straight and Correct in my life,
Scissors to cut off all that Makes me harm and,
Finally, I have Many colors to brighten up my life!

Lauren's Legacy

Lauren Nunes lost her battle with cancer November 26, 2001. She bequeathed her poetry to her mother, Mimi Nunes. Lauren's poems chronicle the intensity of her emotions and fears, as well as the peace she found through her spiritual journey. Here are two of her poems: "Hope," written in December of 2000 and "Unknown," which she penned only six weeks before her death. "She had aspirations of being a writer, among other things," says Mimi. "Her ultimate goal was to have something published."

You can read other poems by Lauren Nunes by visiting the Promise Web page at www.stjude.org/Promise.



Lauren Nunes, age 14

Hope

I am something that you seek
When no one likes you and
Your family thinks you're hopeless.

I am something that you seek
When everyone is in despair and
Everything goes wrong.

I am something that lifts you up
When you are down and
When you are ready to give up.

I am something that will never die
And is with you wherever you are.

I am something that if you are only
Hanging on by a string,
I will pull you up.

I am something that if you have
Led a bad life and want to change,
I will redeem you.

I am a feeling.
All you need to get through the tough times,
I am HOPE.

Unknown

It twists and turns inside you
Tearing at the soft flesh.
You moan and groan in agony
Pleading with it to stop.
"Go away" you shout,
But it only echoes softly in the night.
"What is it?" you wonder.
Only the wrenching pain can answer.
Is there any hope?

"Yes," the angels shout.
You look up into the dark sky
And see what you couldn't see before.
"Where were you?" you say.
He answers, "I've been with you all along."
At first angry, but then humbled
For He did not leave you in the dark.

It grabs you again into a moaning fit.
He touches and holds you. It starts to pass away.
Thank you, you shout. He only smiles.
You don't understand and so many questions come to mind.
He looks at you knowingly, but remains silent.
You start to ask. He raises His hand and
Disappears into the night, but yet He is still there.

You will never know why it happened,
But maybe you can learn and grow from it.
For you will always feel His presence.

St. Jude

By Hanna Haghayeghi

When I first came to St. Jude
I was really scared.

Then I met the doctors
And I knew they really cared.

They said that the treatment would be really tough
But I'm lucky because 6-8 months should be enough.

During my biopsy, the doctors had a scare
Soon I awoke in intensive care.

The nurses helped me when I was in pain
They told me to keep still as they stuck my vein.

I had 29 pokes in just 2 weeks
That was enough to give me the creeps.

Now I have a Hickman line
And that is doing just fine.

Sometimes during my therapy I thought I might die
During those times, I would scream and cry.

I have three to five months of treatment to go
Although the treatment seems to go rather slow.

I can't wait until the day I get out
When it happens I'll scream and shout.

St. Jude will always have a place in my heart.
They have been there for me right from the start.

LAURA HAJAR



Hanna Haghayeghi, age 11

When asked if he knew of any patients who enjoyed writing poetry, Reggie Chavis responded, "Got a piece of paper?" and quickly jotted this tribute to his mother, Sheila Chavis. The engaging young man from Louisiana passed away May 29, 2002, after a valiant struggle with Ewing sarcoma.

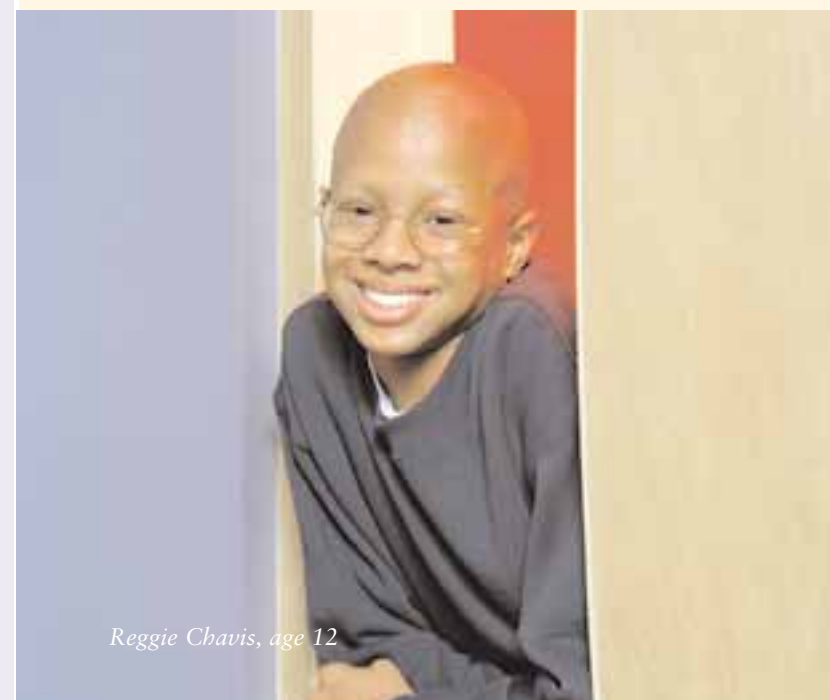
Mom

By Reggie Chavis

Mom is her name,
She loves to play games.
She is my mom and Sheila is her name.

She plays,
She helps,
She pouts,
But I think she hates trout.

She makes me mad by cutting off TV.
I love her,
She loves me.
Thank you, GOD, for giving a mom to me.
Mom—that is what she will always be.



Reggie Chavis, age 12

Claire Reed wrote this poem soon after her frightened 9-year-old daughter learned that she had osteosarcoma, a type of bone cancer, in her left leg. "The poem was written for Shaina, but it was based on Shaina's feelings and thoughts. So it really is her poem, too," says Claire. Mother and daughter recited these words each night at bedtime until Shaina's disease went into remission. In May of this year Shaina, now 12 years old, won top honors for a science fair project chronicling the progression, treatment and remission of her cancer.



Shaina and Claire Reed

For poet and English teacher Mike Oehmann, the best way to take an emotional snapshot is through verse. In "Bedtime Story," Mike captures the vibrant personality of his 6-year-old son, Matthew, and communicates the relief and love of a grateful father. Matthew, who lives in Virginia, underwent treatment at St. Jude for a brain tumor called ependymoma.

Bedtime Story

He squints when he smiles,
Dimples deepen and laughter cascades
As he jumps up and down on the bed.
He dawdles, delaying his bedtime.
He's having too much fun to sleep,
Hopping there in his underpants,
Limbs long, skinny and white.
His scar is a pale scribble along his hairline,
Stretching across his forehead
And dipping to one temple;
A reminder, cold, stark and terrible.
But it's the smile and squint we see now.
It'll take some tickling, some rough house,
Maybe a story. But I'm thanking my lucky stars
And a Guardian Angel or two,
That this boy has miles to go
Before he sleeps.

Side by Side

Side by side
Mommy and me—
Together we'll get through this,
Just wait and see.

Mommy stays with me
Day and night.
I'm not afraid
'Cause it'll be alright.

Side by side
Every day we pray
That things will get better
And go my way.

Cancer is a mean
And ugly cell.
Chemo will kill it,
And make me well.

I miss basketball
And cheerleading too.
Shopping at the mall
And going to school.

Someday I will run
And jump and play.
There is no price
That's too high to pay.

Side by side
A lot of people do care.
Side by side
Good wishes we share.

Side by side
One day at a time.
Side by side
It's gonna take time.



Mike and Matthew Oehmann



PHOTOS BY SETH DIXON

Robert Woodend, 13, is no stranger to pain. Like other patients using the Pain Management Service, he has taken many different medications since arriving at St. Jude in August of 2001. "At one point, he couldn't sleep, because he was hurting all the time," recalls his mother, Julie Woodend. Robert completed his treatment in March. "He's doing great, now," says his mom.

Less Pain, More Gain

St. Jude takes pain management seriously.

BY ELIZABETH JANE WALKER

In November 7, 2000, Tommy Montoya awoke with a sore throat. While the rest of the country flocked to the polls, the high school senior visited his family physician. By the end of the day, America faced a presidential controversy. Tommy faced a diagnosis of acute myeloid leukemia.

A month later, that aching throat was a fond memory, as Tommy lay in a hospital bed, writhing in agony. "He didn't have just one kind of pain," recalls his mother, Libby Montoya. "The bones inside his legs and arms were hurting. The nerves on the surface of his legs and arms were hurting. His shoulders and rib cage were hurting. He had ulcers lining his esophagus from his stomach to his

mouth. That's when they called in the pain team."

The Pain Management Service at St. Jude Children's Research Hospital comprises anesthesiologists, nurses, pharmacists, physical therapists and psychologists who work with patients who have complicated pain issues. Clinicians refer their patients to the service if the children have pain that is unusually complex. "The body of

knowledge for anything in medicine today is so humongous that there is just no way anybody can know it all," observes Libby, who is a registered nurse as well as a

Both Robert Woodend and Tommy Montoya used patient-controlled analgesic (PCA) pumps to help manage pain. The patient receives a continuous infusion of pain medicine, but whenever he needs an additional dose, he simply pushes a button. "Actually, patients may use less medication when they self-administer it compared to when they ask a nurse to bring them a dose of pain medicine," observes Linda Oakes.



St. Jude parent. "The pain team knows what works with different kinds of pain. They know what drugs can augment each other and which ones will interact. You really need one team calling the shots in this area. I've been in health care for 28 years, and I've never worked with a team that has the comprehensive capabilities of this group."

No more bullet biting

Cancer and its treatment almost always cause pain. Tumors press on nerves, bones and organs; radiation damages the skin and mucus membranes; chemotherapy agents inflict brutal side effects. In the past, medical professionals treated pain almost as an afterthought—after all, eradicating disease was the primary goal. As cure rates increased, clinicians recognized the need to alleviate suffering. They learned that by controlling pain they could actually speed recovery. Acute pain increases a patient's heart and respiratory rates, metabolism, blood pressure and stress hormones. Children who are hurting need more oxygen. They have trouble participating in physical therapy or following the mouth-care regimens that are so important for those undergoing cancer treatment. They also experience more depression, anger and insomnia.

"There's good science that has come out that shows that you don't breathe as well when you're in pain, so you get a higher risk of pulmonary complications after surgery," explains Linda Oakes, RN, MSN, St. Jude pain clinical nurse specialist. "Chronic pain influences your immune system, so you don't heal well. You don't eat as well; you don't sleep as well. It really is not just a case of 'Oh, I don't want to hurt'; pain management benefits the whole body. We want our patients to survive and to do that with the least trauma possible."

Doralina Anghelescu, MD, medical director for the Pain Management Service, says the

group provides about 150 consultations a month. "Not all hospitals have pain services," says Oakes. "I think we've been very blessed with the resources to have people dedicated to that service. I would like to see us become the cutting edge in pain management in pediatric oncology. Why shouldn't we be? We're already the leaders in pediatric oncology."

Just say "yes"

St. Jude is well on its way to achieving that goal. The hospital is the only pediatric institution involved in a National Comprehensive Cancer Network project to create standardized pain

guidelines. The new standards will be invaluable to health care workers throughout the country. Most nursing and medical students receive minimal training in pain management. "Sometimes—what is worse—they're taught wrong information," says Oakes. "Clinicians want to do better with pain management, but they have not always been given the education or the tools to do so. We do not want to just treat the patients with complex pain problems; it is just as important for us to help the patient's primary team know how to treat that pain. We do that by attending rounds and learning from them what is going on with the patients. We work together as a team to help all clinicians improve their own ability to treat pain experienced by children at St. Jude."

Some health care workers have been taught that children, especially infants, cannot feel pain. "Many studies have shown that infants do feel pain, and that they can remember it in subtle ways down the road," says Oakes, who has published several journal articles and book chapters in her field. Another myth is that the use of prescription narcotics often leads to addiction. "I've been working in pain management formally for six years, and I've not seen one patient who has become addicted because we gave narcotics for pain," Oakes says.

Pain Management staff take every opportunity to educate families and re-educate staff members through consultations, in-service training and lectures. Team members study the medical literature and travel the country searching for innovative treatments. They write pain management policies for the institution, and they educate nurse practitioners, pharmacists, residents and fellows who work at St. Jude. "Pain management is such a growing science that we're learning all the time about better ways to do it," says



In May of 2001, Tommy Montoya was so weak that he could not push the button to give himself morphine during his high school graduation ceremony.

Oakes, who has traveled to El Salvador and Venezuela to teach nurses through the St. Jude International Outreach Program.

Members of the service are also researching better strategies for treating pain. St. Jude recently participated in a multi-site study that used fentanyl patches to provide pain relief for children. The patches adhere to the skin and continuously deliver a narcotic that controls pain. Traditionally, the patches have been used for adult patients; the St. Jude study found that ones containing smaller doses of medication could be used successfully on children. "Ultimately, the drug company we worked with will make these patches available on the market," says Anghelescu. Other upcoming research projects include a study to determine the best way to give anesthesia for procedures and projects to evaluate new methods for managing postoperative pain.

Solving the puzzle

Tommy Montoya's case challenged even the most seasoned pain specialists. "He was just such a puzzle," recalls Anghelescu. "Every day we struggled with something new." Tommy suffered from multiple kinds of pain simultaneously, and the pain changed as his treatment progressed. "He was on different concoctions of things at different times," recalls Libby, "different combinations of morphine, as well as other drugs to treat the bone pain. He would swallow lidocaine to deaden the pain from his mouth and throat ulcers. Then he developed peripheral neuropathy, which means that the nerve endings were inflamed from the chemotherapy."

In March of 2001, Chris Montoya donated bone marrow so that his brother could undergo a bone marrow transplant. Then the unthinkable happened:

Tommy developed Guillain-Barré syndrome, a rare disorder in which the immune system attacks part of the peripheral nervous system. Tommy was almost totally paralyzed. "The nerves that control your motor activities disintegrate in Guillain-Barré," says Libby. "The paralysis doesn't go away until those nerves grow back. As they grow back, the nerves are very sensitive. So now Tommy had another source of pain."

One Saturday evening, Tommy lay in the hospital, tormented with horrendous pain that seemed impervious to treatment. The St. Jude staff called Anghelescu at home. All night, she searched for a way to diminish Tommy's suffering. At 6 a.m. Sunday morning, she walked into Tommy's hospital room and handed a journal article to his mother. "This is what I'd like to try with Tommy. I want you to see it and understand it," she told Libby.

"During the night, Dr. Anghelescu had found an article on the Internet about a cardiac drug, and how it could interact and block the spastic nerve endings to prevent the pain," says Libby. "She cared enough about me as a person and as a cardiac nurse to recognize that I was going to want to know how this drug works. And it was amazing. It worked!"

"I have a special spot in my heart for Dr. Anghelescu for many reasons," Libby continues. "But I will never forget how she took her weekend to search the Internet and find something else to make my child better."



Linda Oakes, RN, MSN, St. Jude pain clinical nurse specialist, is always ready to share pain management tips. In her rolling red "library," she trundles educational materials for staff members and informational publications for patients and parents.

Teamwork works

Although Tommy does not recall much of his treatment, he vividly remembers the neuropathic pain. "You know the sensation you get when your leg's asleep—a shooting tingling?" he asks. "I'd get those up and down my legs all day long and all night long."

The clinical pharmacist on the service is routinely consulted for dosing recommendations for various medications used to treat pain. John McCormick, PharmD, admits that Tommy's case was complicated. "We thought we had used every class of pharmacologic agents that were available to treat Tommy's pain," he says. "Then Dr. Anghelescu proposed the use of the cardiac drug. Since

we had previously had very little experience with this, it meant doing a little research on my part to come up with the best way to deliver the therapy. Fortunately, we were successful."

The Rehabilitation Services department provided Tommy with support garments to compress his throbbing nerve endings. "Sometimes pain can be associated with inactivity," says Lola Cremer, a physical therapist and member of the Pain Management Service. "We also helped Tommy by enhancing his mobility, which reduced some of the discomfort related to prolonged inactivity."

Pain Management Service psychologists assisted Tommy in dealing with the inevitable feelings of depression that accompanied his interminable battle with pain. "In the first six weeks of his senior year in high school he was told that he had leukemia. For the next year, he spent every holiday as an inpatient. That's depressing," says his mom. "But members of the pain team knew about an antidepressant that also helped with neuropathic pain."

Mark Miles, PhD, and his colleagues in Clinical Psychology wield an arsenal of behavioral weapons in the war against pain. Many Pain Management Service patients learn to fire those weapons. Relaxation techniques help children counter the body's

physiological responses to pain. Systematic desensitization exercises reduce their anxiety levels. Clinical psychologists at St. Jude also use hypnosis, visual fixation points and guided imagery to block out pain. "You don't eliminate the pain experience, but you do reduce the degree of mental processing that is given to it," explains Miles. "There are so many aspects of treatment that children have no control over. By using tools to help manage pain, they feel that they're doing something that contributes to their health and welfare. Nothing lifts somebody out of a feeling of helplessness as much as having success."

Members of the Pain Management Service say they find fulfillment in contributing to that success. "Many times, children come into the Pain Clinic miserable, and when they leave my area they're smiling and saying 'Thank you,'" says Alisha Broglin, RN. "Parents come in tense and in tears, and they leave relaxed and smiling. That's when you know you've made a difference."

Life after pain

In May of 2001, Tommy left St. Jude for four hours to attend his high school graduation. He was so weak that he could not push the button to give himself morphine during the ceremony. "He would turn in his wheelchair and say, 'Mom, I need more morphine,' and I'd punch the button for him," says Libby.

In the ensuing months, Tommy's pain diminished and his strength gradually increased. In January of this year, Tommy drove to St. Jude and returned his wheelchair, braces, canes, crutches and other assistive devices. He didn't need them any more.

"Tommy's still with us, and he's leukemia free," says his thankful mother. "And that made it all worthwhile." ●



Doralina Anghelescu, MD, medical director for the Pain Management Service, pauses with Tommy Montoya during his recent visit to the hospital. This fall, Tommy plans to enroll in college, where he will study computer engineering.

Perspective

In 1965, she was patient No. 504 at a fledgling hospital called St. Jude. Today she's a cancer survivor. A blood donation advocate. A mom.

By Daphne Dawn Harrison Terral



Daphne, Scott and Elliott Terral

I was only 4 years old when I began having recurrent bouts with what a rural country doctor diagnosed as a stomach virus. The doctor assured my mother that I would get over it, and that we should just let it run its course. But finally my mother took me to a pediatrician in Clarksdale, Mississippi, who realized that I had Wilms tumor, a cancer of the kidney. I traveled to Memphis to have surgery and to undergo radiation treatments at St. Jude Children's Research Hospital. Today, I am a healthy 41-year-old. I remember much of my stay in 1965, but one aspect of my relationship with St. Jude that many supporters probably don't know is the long-term commitment they provide to former patients.

exam, the doctor determined that everything was perfectly fine. Then he informed me that I was being released as an outpatient. It meant that I did not have to return to St. Jude again.

When I was 8, 10, 12, even 20 years old, I prayed for the day that I would not have to go back to the hospital for a check-up. But when that day finally arrived, I was shocked, surprised and deeply saddened by the prospect of being separated from this institution that had meant so much to me.

It was a very emotional day. I remember driving out of the parking lot and looking back to remember the scene forever. Even though the After Completion of Therapy Clinic keeps in touch with me

"Even though I have 'grown up and moved away,' I am still part of the family."

I will never forget my last outpatient visit. I went through the usual battery of routine tests and then waited patiently for the doctor to enter the examination room. After the

through regular correspondence, I still miss the St. Jude experience. There was something about going back to the place where I had defied the odds and survived. It was a blessing to those who had treated me, and a blessing for me to be able to thank them again. I was a part of a family there, and even though I have "grown up and moved away," I am still part of the family—it is just a different dynamic in the relationship.

I have worked in volunteer blood banking services for the past 11 years. It is a very fulfilling and rewarding profession. I get to share my story and tell others how important blood donations are to cancer patients.

When I was going through therapy at St. Jude, they could never tell me if I would be able to have children. They just didn't know. But I did have a son. He is 9 years old. His name is Elliott Terral, and he is just awesome.

Thanks to my St. Jude "family"—my lifesavers—I now have a family of my very own. •

Daphne Dawn Harrison Terral and her family live in Louisiana.



St. Jude patient Jody Burton Hooper doesn't wait in waiting rooms. He draws. Whenever he comes for checkups, the young Texan packs his sketchpad along with his toothbrush. Since arriving at St. Jude at the age of 12, Hooper has created scores of drawings—catching fellow patients and family members in action. In the rendering above, a teen-aged St. Jude patient spends a quiet moment rocking another patient in a common room at the Ronald McDonald House. "I knew I wanted to be an artist when I was 5," says Hooper, who originally came to Memphis with a rare brain tumor called an astrocytoma. Now, many years later, as Hooper undergoes treatment for a recurrence, he continues to capture the world around him on paper. He says he tries to give viewers of his art "a glimpse of something beautiful or kind." He believes that a positive mindset is of paramount importance when a person is undergoing hardships. "Attitude is everything," he asserts. "I'm going to live!"