Charmel Vaughn: Sound Rebound
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.
The gene scene
March 2002 issue of Nature

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 AML (acute myeloid leukemia) in laboratory mice should assist scientists studying cancer in humans.

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 solid-tumor cancers in adults and children.

One simple act has far-reaching consequences.

Summer 2002 Promise

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 and developing new targeted treatments.

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 of Nature Structural Biology and used rabbit proteins purchased from commercial sources.

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

Highlights

Cancer Cell

Structural Biology

Psychosomatic Medicine

Nature

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.

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. 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.

The discovery could shed light on the pathology of neurological diseases such as Alzheimer’s disease, Parkinson’s disease and retinitis pigmentosa, and may help doctors better understand some nervous system disorders.

“The discovery could shed light on the pathology of neurological diseases such as Alzheimer’s disease, Parkinson’s disease and retinitis pigmentosa, and may help doctors better understand some nervous system disorders,” says James Downing, MD, chair of St. Jude Pathology.

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.

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

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

ST. JUDE patient Charmel Vaughn blends RAP with RELIGION.
Steady spreadin’ the word of Jesus
gon’ die,
and the message is deadly serious:
sophisticated, the language is hip
deep rap. The instrumentals are
ble excitement. Bodies begin to
atmosphere with an almost palpa-
usual pressures of youth.

Teen faces challenges beyond the
ment, an assortment of prescription
Near the high-tech recording equip-
tal, just by hanging out in the Teen Room and sharing his music.

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

“You Never Know” was a natural response to a
musician who says he’s “saved and
not contemplated their mortality
might be surprised that a teen
plays such apocalyptic
Charmel has always focused on
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 hos-
pital’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.

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“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 mod-
est,” 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 can-
cer. 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 church-
es” 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 hap-
pens to me,” says
Charmel. “I think the
Lord took care of me
through the whole thing.
Of course, prayer helped

Near the high-tech recording equip-
ment, 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 palpita-

Charmel by hanging out in the
hospital’s Teen Room and sharing his music.

Charmel aspires to earn a degree in

Summer 2002 Promise
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?”

Critics of rap music howl that the milieu glorifies profanity, endorses violence and deems women, Those detractors are correct, in some instances. But is the ethos of rap music morally incompatible with the values of conservatism? 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 rap than to anything else.” Indeed they are. In the last year.

“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.

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 culinarian 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.

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 arroz 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.
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 sweep the MLB Finals, 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 hospital’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.
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 it was not so clear a year ago. ALL seems like a no-brainer now, but 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 the 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, bioinformaticians and pathologists. “We have a unique population of samples because we’ve treated our patients in a uniform way,” Downing observes. “We 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 predicted 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. Soon, such a wait may be a thing of the past, thanks to new techniques developed by St. Jude scientists.

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
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 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.”

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

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.

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.

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Mom—that is what she will always be.
On 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 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 management 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.
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.

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 worked. And it was amazing. It worked! “I have a special spot in my heart for Dr. Anghelescu,” says Libby. “So many reasons,” Libby continues. “But I will never forget how she took her weekend to find the article and find something else to make my child better.”

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.”

We also had Tommy working with the 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, they cry, 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.

During the night, his mom would wake up with the discomfort related to prolonged inactivity. “I have a special place in my heart for Dr. Anghelescu,” says Libby. “So many reasons,” Libby continues. “But I will never forget how she took her weekend to find the article and find something else to make my child better.”

Doradina 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.
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.

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 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 through regular correspondence, I still miss the St. Jude experience. 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 “famil–ly” — my lifesavers — I now have a family of my very own. •

Daphne Dawn Harrison Terral and her family live in Louisiana.

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