



DJ Pete

A Step in the Right Direction

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St. Jude steers tiny DJ Pete onto the right path.

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For this couple, gratitude is a way of life.

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Keep Climbing



Promise

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DJ Pete and his St. Jude
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Research Highlights

Serious silliness

The Child Life Program strives to minimize the stress and anxiety of children undergoing treatment at St. Jude. In addition to providing age-appropriate explanations and preparations, the staff creates opportunities for play and expressive activities that promote an outlet for feelings and peer interaction. One such event is Silly Field Day, in which patients, family and St. Jude employees such as Child Life Specialist Mirna Brindas face off in friendly combat.

SETH DIXON



Analyzing the AML genome

The most comprehensive analysis yet of the genome of childhood acute myeloid leukemia (AML) found only a few mistakes in the genetic blueprint, suggesting the cancer arises from just a handful of missteps, according to St. Jude investigators. The research appeared in *Proceedings of the National Academy of Sciences* in July 2009.

"The complement of genetic lesions varies across the different genetic subtypes of AML, but there are very few lesions in total. That is surprising. Most cancers have lots of alterations," said James Downing, MD, St. Jude scientific director and the paper's senior author.

Downing said the findings underscore the need to survey the entire genome of childhood AML and take a more detailed look at particular AML subtypes.

"This rigorous systemic genome-wide study was an important step to direct our future efforts to the most effective strategies to pinpoint lesions in AML," added Ina Radtke, PhD, Pathology, the paper's lead author.

PETER BARTA

Trading needles for magnets

St. Jude researchers have found that magnetic resonance imaging (MRI) is just as accurate for measuring the body's iron levels as analyzing a liver biopsy sample. Such measurement is critical to guide treatment of iron overload.

"Iron overload happens because a patient needs repeated blood transfusions to treat such disorders as sickle cell anemia and thalassemia," said Jane Hankins, MD, of Hematology, the study's lead author. "This iron accumulates in critical organs, and it can cause failure of these organs." In the past, monitoring iron levels required periodic biopsies.

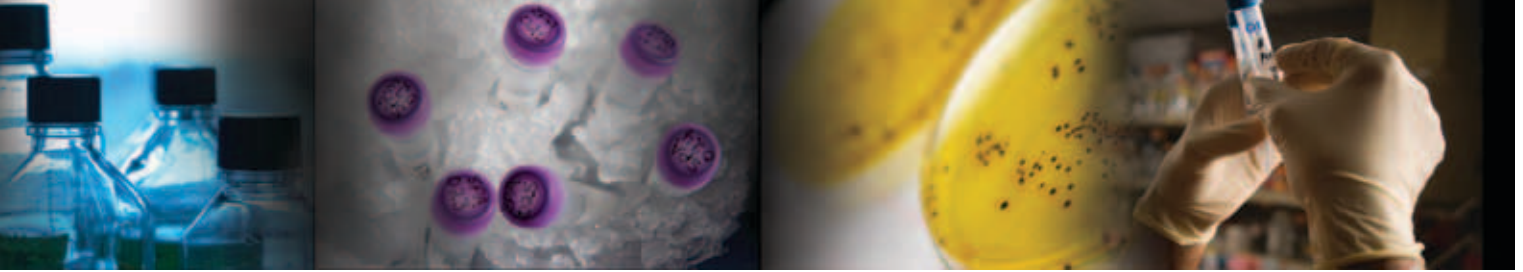
"Based on results of our study, we feel confident in relying on MRI from now on, without the need for biopsy," added Claudia Hillenbrand, PhD, of Radiological Sciences, the study's senior author. Results of this study appeared in the journal *Blood* in May 2009.

Spotlight on survivors

An extensive study of more than 2,800 long-term survivors of childhood central nervous system tumors details risks some survivors face decades after diagnosis. The risks include the return of or spread of the original cancer, the diagnosis of a new second cancer and an elevated incidence of other health problems.

The findings were published in the *Journal of the National Cancer Institute* in July 2009. The work is part of the Childhood Cancer Survivor Study (CCSS), a collaborative effort of 30 institutions, for which St. Jude is the central coordinating institution.

Greg Armstrong, MD, of Epidemiology and Cancer Control, said the results highlight the continuing health care needs of childhood cancer survivors. "This population needs high-quality, long-term follow-up, preferably by a cancer center such as we have here at St. Jude," said Armstrong, the paper's lead author and a CCSS project director.

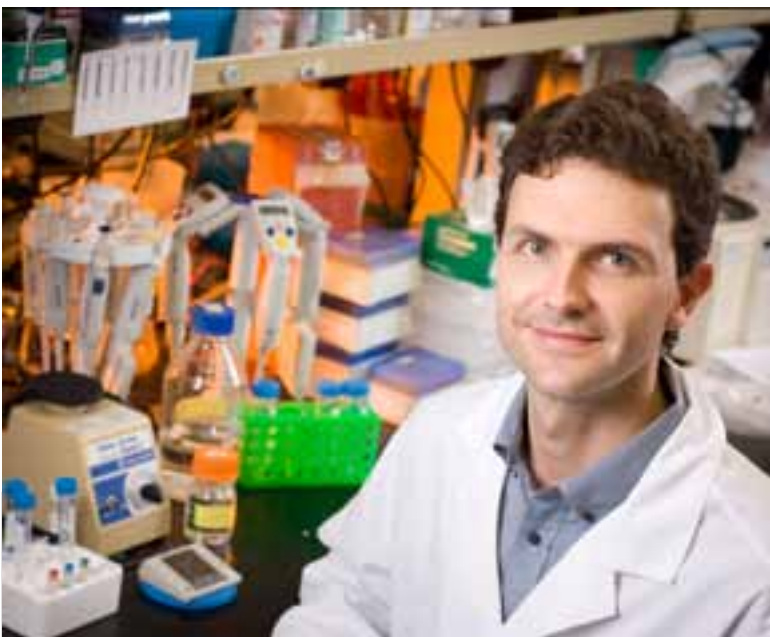


A peek into the immune system

St. Jude investigators recently reported new details of the complex dance that helps maintain immune balance. The work highlights the role that a small protein known as interleukin 35 (IL-35) plays in regulating suppression within the immune system. IL-35 is a novel member of a larger family of signaling molecules, known as cytokines or in the immune system as interleukins, which cells rely on to communicate and to influence how cells behave.

Originally identified in the laboratory of Dario Vignali, PhD, Immunology, IL-35 is one of just three cytokines that dampen rather than fuel the immune response. The new findings build on the laboratory's earlier work that suggested IL-35 was central to the regulatory function of lymphocytes known as regulatory T cells.

The work suggests new treatment and prevention targets for a variety of human diseases, including arthritis, allergies and the inflammatory response following an infection. A report on this research appeared in *The Journal of Immunology* in May 2009.



Mullighan named Pew Scholar

Charles Mullighan, MD, PhD, of St. Jude Pathology has been named a 2009 Pew Scholar in the Biomedical Sciences. Pew Scholars are junior faculty members at medical schools and research institutions who show outstanding promise in research that is related to the advancement of human health. The Pew Charitable Trusts selected 17 of the country's most promising early-career scientists to receive the award.

Mullighan's research focuses on the use of high-resolution, genome-wide approaches to identify genomic aberrations contributing to leukemogenesis and influencing leukemia outcome; the use of *in vitro* and *in vivo* experimental approaches to model genomic abnormalities in leukemogenesis; and the genetics of disease susceptibility and disease phenotype.

Other Pew Scholars at St. Jude have included Brenda Schulman, PhD, of Structural Biology and Genetics/Tumor Cell Biology; Michael Dyer, PhD, of Developmental Neurobiology; and Joseph Opferman, PhD, of Biochemistry.

Mechanism for migration

The molecular machinery that helps brain cells migrate to their correct place in the developing brain has been identified by St. Jude scientists. The finding offers new insight into the forces that drive brain organization in developing fetuses and children during their first years. Disruption of this brain-patterning machinery can cause epilepsy and mental retardation, and understanding its function could give new insight into such disorders.

Basic understanding of the migration machinery could have important clinical implications.

"If we more clearly understand how neurons migrate in neural development, we will have a better framework to explain the basis of neuronal migration defects in children," said David Solecki, PhD, Developmental Neurobiology. "Also, cell migrations may contribute toward the spread of brain tumors in children. If we can understand how normal neurons migrate, we might be able to dissect the machinery of the migration of brain tumor cells."

The researchers published their findings in the journal *Neuron* in July 2009.

Research Highlights

Targeting high-risk leukemias

A research team has pinpointed a new class of gene mutations that identify cases of childhood acute lymphoblastic leukemia (ALL) that have a high risk of relapse and death. The finding suggests specific drugs to treat this high-risk leukemia subtype. A report on this study appeared in *Proceedings of the National Academy of Sciences* in May 2009.

“We have made such great progress in curing children with ALL that the main challenge is now the remaining high-risk patients,” said the report’s co-senior author, James Downing, MD, St. Jude scientific director.

Analyzing leukemic cells from patients with high-risk ALL, scientists discovered mutations in about 10 percent of the cases in a family of protein kinases called JAK, whose members are also mutated in other types of leukemias and related diseases. In some children, JAK mutations appeared to work in concert with a mutation in the gene *IKZF1*.

In further studies, the researchers plan to identify mutations in kinase genes and other enzymes that underlie high-risk ALL, as well as explore how these abnormalities might work together to drive the cancers.

“We have made such great progress in curing children with ALL that the main challenge is now the remaining high-risk patients.”

SETH DIXON



Science in the summer

The Summer for Sickle Cell Science Program brings Memphis-area high school students into St. Jude science, research and medical environments for eight weeks each year. Funded by the National Institutes of Health, the program gives teens hands-on experience that could inspire them to pursue science or medical-related careers. Participating in this year’s program were (back row, from left) Julian Earl, Bronson Worthy and Lowell Hays. The students worked in the Hematology department labs of, respectively, Russell Ware, MD, PhD, Hematology chair (seated, at left); Derek Persons, MD, PhD (seated, at right); and John Gray, PhD (standing, at right).

St. Jude produces cancer-killing immune cells

St. Jude scientists have created a strategy that dramatically boosts production of natural killer (NK) cells for cancer treatment.

In a single week, the patented technique generated a 100-fold increase in NK cells, which are a powerful, but rare immune component. Laboratory research showed the new cells were more efficient cancer killers than NK cells from other sources. A report on this work appeared in the journal *Cancer Research* in April 2009.

Scientists have been eager to obtain the cancer-fighting cells, which account for just 5 to 10 percent of lymphocytes. “The challenge was to expand NK cells to get adequate numbers for treatment,” said the paper’s senior author, Dario Campana, MD, PhD, of Oncology and Pathology. “People have been trying for decades but have only had modest success.”

The finding prompted requests from many laboratories worldwide for the St. Jude cells. The results also helped launch a Phase 1 study of the NK cells in St. Jude patients battling Ewing sarcoma, rhabdomyosarcoma and certain leukemias.

The Cross Foundation: Giving with Thanks

With a spirit of gratitude, Rob and Connie Lawrence teach by example.

BY JANICE HILL

For Rob and Connie Lawrence, charitable giving is more than a philanthropic financial decision. It's a way of life, a method of teaching, and perhaps most importantly, an expression of faith.

The couple established a private foundation approximately 10 years ago to ensure that their giving could continue and grow throughout their lives and beyond. Rob explains that they named it The Cross Foundation Trust as a symbol of the blessings they have been given. "It is a way we can give thankfully to help others in a mission driven by our faith," he says.

While considering which efforts to support two years ago, Rob and Connie happened to watch a television program about St. Jude Children's Research Hospital that aired as part of the *Thanks and Giving®* campaign.

"We had seen [National Outreach Director] Marlo Thomas talk about St. Jude several times before, but something about that particular program really drew us in," Connie recalls.

"We've always been thankful for our healthy children, and we realized how giving to St. Jude would be a way to express our gratitude," Rob adds.

Their large donation to St. Jude was made as a gift to their four adult

daughters and families. The couple created a package of information about the hospital's mission and lifesaving work, wrapped the package and presented it to their children after they had opened their other Christmas gifts.

"It was really a teaching moment," Connie says. "They were very touched." The couple had intentionally involved their children with charitable giving in age-appropriate ways throughout their lives. When their daughters were in high school, each girl received money to donate to the charity of her choice. The sole stipulation was that only charities that spend a limited percentage of donated funds on fundraising should be chosen.

Although the Lawrences usually select different charities for their most sizable gifts each year, they say they have repeated their gift to St. Jude in part because of the hospital's cutting-edge research and its commitment to share its findings with medical communities worldwide.

A retired investment manager with Fidelity, Rob says that setting up a private foundation was right for their family. His investment expertise gives him the ability to manage and focus the foundation's assets.

He recommends that individuals



Rob and Connie Lawrence involved their children in charitable giving throughout their lives.

who care about charitable giving but who may have less financial expertise consider setting up donor-advised funds at investment companies they trust.

"They will be able to realize immediate tax advantages, and when securities begin appreciating again, they will be able to direct more to charities while avoiding capital gains taxes," he says.

The Lawrences enjoy dividing their time between their homes in Massachusetts and South Carolina and spending time with their three grandchildren, the oldest of whom is 3 years old. Gradually, Rob and Connie intend to teach their grandchildren lessons in charitable giving as they did with their own children.

"There is a scripture that basically says, 'To whom much is given, much is required,'" Connie says. "God has blessed us to be a blessing to others. Those are not just words. It is an obligation."

Foundations that would like to learn more about St. Jude can call (800) 830-8119 or e-mail foundations@stjude.org. ●

ROLL MODEL

With help from St. Jude, **Michael MILLER** transcends obstacles in his way.

BY ELIZABETH JANE WALKER

At first glance, Michael Miller's bedroom resembles the lair of a typical teenager. Rumpled T-shirts and ragged jeans have been strewn across furniture and floor. Posters, skateboard decks and castoff guitars float on sky-blue walls. But closer examination reveals creativity blooming amid the chaos. Items mounted on the walls are arranged with a certain artistic flair. The presence of well-used musical instruments, loop pedal and amplifiers attest to the fact that, for Michael, art is serious business.

With his subtle, half-smile, quiet voice and serene eyes, the teen seems an unlikely rocker. But for hours each evening, he hunches over his guitar. One moment, his fingers fly across the frets with feverish intensity; the next, they caress the instrument slowly and deliberately. When he's not practicing, Michael hurtles down sidewalks

and streets on his skateboard, wheels clattering across the seams like a locomotive chugging along a track. If he encounters an obstacle—a ledge, a set of stairs, a flat, open space—he flings his arms out for balance, twirling, leaping and launching himself toward the heavens.

"Skating's a pastime, but music is my passion," Michael says. During the past two years, these activities, along with a deep faith and extraordinary medical care, have helped him rise above even the most daunting challenges.

No fear

In July of 2007, Michael was perplexed and annoyed when, 10 days after his 16th birthday, he began exhibiting signs of a serious stomach virus. After a couple of days, Kimberly and David Miller took their son to the doctor,



For the past two years—whether playing guitar or skateboarding—St. Jude patient Michael Miller has refused to allow a stage IV rhabdomyosarcoma diagnosis slow him down for long. “If we had not gotten to St. Jude when we did, Michael would most likely not be with us today,” says his mom.

who discovered a large lump in Michael's abdomen. "You need to take your child to the emergency room," he told the Millers.

During the whirlwind that followed, Michael underwent an operation to remove what doctors believed to be the primary tumor. Afterward, the local hospital sent the teen home to recuperate. Minute by minute, hour by hour, Michael's condition worsened. "I was so scared," Kimberly says. "He was throwing up all the time. He couldn't stand or walk. I thought it was the end. We didn't know whether he would still be with us from one day to the next. When it would get too bad, we would take him to the ER, where they would give him fluids and send him back home. There was a hopelessness that came over us during that time."

Kimberly and David found support and strength from the most unlikely place—their own son.

"At first it was pretty freaky, and I was scared," Michael admits. "But the night after my surgery I prayed all night long. After that, I knew everything was going to be all right." Then he calmed his parents' fears and helped them focus on the task ahead.

"God's going to see me through this; I'm not going to worry about it," Michael told them. "Now, where's the best place we should go?"

Rain on the windshield

For years, the Millers had heard about St. Jude Children's Research Hospital through television and word of mouth. They asked their physician for a referral. By the time they arrived in Memphis, Michael was extremely sick. "If we had not gotten to St. Jude when we did, Michael would most likely not be with us today," Kimberly says.

Physicians quickly determined that Michael had stage IV rhabdomyosarcoma, an aggressive, soft-tissue tumor that accounts for 7 to 8 percent of childhood cancer cases.

Michael's situation was so precarious that clinicians had to stabilize his condition before treatment could begin. "Michael was very ill," recalls Sara Federico, MD, Oncology fellow. "On the scans, the tumors looked like rain on a windshield. His abdomen had large masses, which were conglomerations of multiple lymph nodes. His bone marrow was packed with disease, and he had multiple lesions in his lungs, and bone. Simply stated, Michael was critically ill on arrival to St. Jude."

According to Wayne Furman, MD, interim director of the Solid Tumor Division, the cancer actually caused a fracture in Michael's vertebra. "The bone was weakened so much by the tumor that it compressed," he explains.

Clinicians enrolled Michael in a protocol for high-risk rhabdomyosarcoma. Furman says the treatment plan entails intensive chemotherapy with six drugs for 51 weeks, plus radiation and surgery. The study incorporates a combination of drugs that St. Jude molecular pharmacologists had previously shown to be highly effective against the disease.

On a roll

Almost immediately, Michael's condition improved. "He had a remarkable response," Federico says. "His disease truly just melted away."

The treatment took its toll on the teenager, who became super-sensitive to scents. "To me, the radiation smelled like iodine," he says. "People would come to Ronald McDonald House and serve these amazing meals. But when I'd get near the kitchen, I'd smell the food and I'd turn and run for my room."

As a result, the 5-foot, 9-inch teen's weight dropped to 110 lbs. Michael credits John Franklin, RN, with helping him gain weight. "When I was in the hospital, John would come into my room and tell me what looked good in the cafeteria that day. Or he would get me takeout if the nurses were ordering," Michael says.

Like many teens, Michael was tethered to his cell phone, fingers constantly tapping out text messages to friends. His mom laughs that he could text during medical procedures or even in his sleep. "One time, Michael was

Facts about rhabdomyosarcoma

Rhabdomyosarcoma, a cancer that forms in the soft tissues, consists of cells that normally develop into skeletal muscles. The tumors can arise virtually anywhere in the body.

Although rhabdomyosarcoma is the most common soft tissue cancer in children and adolescents, only 350 cases are diagnosed in the United States each year.

More than 70 percent of children with localized rhabdomyosarcoma experience long-term survival.

St. Jude investigators are determined to increase the current survival rates. Several studies are ongoing to identify the most effective drug combinations to combat the disease. Clinicians are also interested in reducing the amount of radiation that is required to ensure a cure while minimizing the long-term side effects of treatment.



(Left) As part of his protocol, Michael received a combination of drugs that St. Jude molecular pharmacologists had shown to be highly effective against rhabdomyosarcoma. “His disease truly just melted away,” says Sara Federico, MD, Oncology fellow.

(Center) Michael continued to play his guitar throughout his intensive chemotherapy treatment.

(Right) John Franklin, RN, found many ways to encourage Michael during his treatment. During a recent visit to the hospital, Michael demonstrated his musical skills for Franklin.

actually sedated and they were about to put the needle into his spine when he tried to reach for his cell phone,” she says.

Occasionally, Michael would slip away from the watchful eye of clinicians, grab his skateboard and practice ollies, grinds and kickflips. For just a while, he would be a carefree teenager once again.

“He didn’t tell me about that until after he finished therapy,” says Federico with a rueful laugh. “It used to make me nervous when he would go home for visits, because I suspected that he was skateboarding.”

In spite of her fears about his activities, Federico learned to respect the teen for his maturity and positive attitude. “Michael was a joy to take care of,” she says. “He was well aware of everything he was missing at home. He couldn’t play in his band or hang with his friends. But he went through everything with a smile. I never heard him complain about chemo or radiation therapy. I never heard him complain about the fact that he was throwing up. He never complained. Ever. He acted like treatment was a piece of cake, when it wasn’t at all.”

Gradually, Michael’s strength improved and the tumors disappeared one by one—even the softball-sized mass in his abdomen. The lesions in his lungs were the last to go. Today, his disease is in remission.

Back to the grind

David and Kimberly say they are grateful for the kindness they were shown at St. Jude. “I don’t care where you go at that hospital, they make you feel at home and they treat you like family,” Kimberly says. “We’ve never received a single bill for his treatment. They took all that worry from us. We already had so many things running

through our heads, but St. Jude did everything they could to make it easier for us. The shuttle would meet us at the airport; we were given meal cards; we were given a place to stay. Everything was done for us, so that we could concentrate on helping Michael get better.

“We’ve been really blessed, and we know it,” she continues. “We don’t take that for granted.”

Hospital staff recently asked Federico why Michael’s hands, feet and calves were glowing on a routine PET scan. “The scans can light up in places where you have disease,” Federico explains, “but they can also light up in places where there’s a lot of activity. You can literally look on Michael’s PET scans and know that he does a lot of skateboarding and guitar playing.”

A self-taught musician, Michael played in several rock and Christian rock bands before his diagnosis. The quiet, self-effacing teen says that he loves to perform in front of crowds. “Sometimes I get a little nervous,” he admits, “but the experience pushes you to grow.” He also enjoys teaching music and hopes to pursue that as a career. His mom wants him to enroll in a music program in a Texas college; he has his hopes pinned on one in Boston, Massachusetts. Wherever he lands, Michael plans to augment his current skills in guitar, bass and percussion with training in violin and piano. “It’s really exciting,” Kimberly says. “It’s just going to be phenomenal to see what he can do when he gets to college.”

In July, Michael turned 18 and, like many teens and most musicians, opted to get a tattoo. But, like everything else he does, this one was artistic and profound. “I decided to get a cross with wings behind it,” he says. “It symbolizes how faith can carry you through everything.” ●

Give thanks.

The hospital's sixth *Thanks and Giving* campaign shares the mission of St. Jude with people throughout the nation.

BY AMANDA MCGEE ROBBINS

JOHN ZACHER



National Outreach Director Marlo Thomas kicks off the *Thanks and Giving* season with a little help from (clockwise from top) Kennedy Pepper, Emmanuel Drain, Will Patton and Tyron Hunter.

Since 2004, holiday shoppers throughout the country have generously supported the children of St. Jude Children's Research Hospital by giving during the annual *Thanks and Giving*[®] campaign.

Even a sputtering economy could not dampen the dedication of employees representing the more than 50 corporate partners who participated in the 2008 campaign. They encouraged customers to give

to St. Jude through add-ons at the register or by purchasing specialty merchandise. As a result, millions of American consumers supported the lifesaving work of St. Jude despite gloomy economic news. Holiday shoppers purchased plush pandas at Kay Jewelers and chocolates at Target. At Kmart, Dick's Sporting Goods and AutoZone, they added donations to their purchases.

Those companies and others are poised to repeat that success

this year when the sixth annual *Thanks and Giving* campaign kicks off November 27, the start of the nation's busiest shopping season. Created by Marlo, Terre and Tony Thomas, the children of St. Jude founder Danny Thomas, this national fundraising campaign has become a holiday tradition. The campaign's signature call to action—"Give thanks for the healthy kids in your life, and give to those who are not."—truly resonates with consumers.

Raising awareness

During *Thanks and Giving*, people across the country will learn, through a series of print, broadcast and Internet ads, about the remarkable strides St. Jude is making in curing and treating catastrophic childhood diseases. Celebrity friends Jennifer Aniston, Robin Williams and Antonio Banderas will once again appear in television spots for *Thanks and Giving*. And the work of the hospital will be prominently featured on such network programs as NBC's *TODAY* show.

Thanks and Giving will have an added awareness dimension in 2009 to broaden its reach to the Spanish-speaking population. Joining the campaign this year is the popular

Puerto Rican musician and actor Luis Fonsi, who will share the mission of St. Jude through the Spanish-language media.

Beginning in November, the *Thanks and Giving* magnifying glass logo will be prominently displayed in stores across the country and online, helping shoppers identify the retailers who are joining St. Jude in the fight against deadly childhood diseases. Many organizations have signed on as *Thanks and Giving* partners; some, like CVS/pharmacy, have committed to raising millions to name special programs at the hospital.

This fall, the CVS Caremark Rehabilitation Services Center will be dedicated at the hospital. CVS/pharmacy became a corporate partner in the inaugural *Thanks and Giving* campaign in 2004 and runs an add-on program in more than 7,000 locations throughout the United States and Puerto Rico. The company has raised more than \$13 million for St. Jude and is committed to raising at least \$16 million for the expanded rehabilitation services center. CVS/pharmacy raised more than \$5.2 million in the 2008 *Thanks and Giving* campaign.

"CVS/pharmacy is an example of the ongoing dedication of our *Thanks and Giving* partners and shows the support the American people have for the St. Jude mission," says John Remington, ALSAC senior vice president of Corporate Alliances.

Reaching others

Building on the success of previous *Thanks and Giving* campaigns, this year's effort will see an expanded *Give thanks. Walk.* program, plus a new online opportunity to raise funds and awareness for St. Jude. The program was held for the first time last year, when St. Jude supporters descended on shopping malls in 15 cities across

the country for a 5K walk. This year's event will be held November 21 and has expanded into 40 markets.

New this year are interactive ways for people to individually tailor their support for the children of St. Jude. *I give my voice* encourages Facebook and Twitter users to post messages about their support of St. Jude and become online advocates for the hospital.

Through *I give my vision*, visitors to the *Thanks and Giving* Web site can use YouTube to post videos detailing why they support the hospital or share existing St. Jude videos with others. Visitors to the *Thanks and Giving* site can also choose *I give my energy* and volunteer to fundraise on behalf of St. Jude and become online fundraisers for the hospital.

Giving hope

Throughout the holiday season, the *Thanks and Giving* campaign offers numerous opportunities to spread the word about how the work

at St. Jude has changed treatments for cancer and other catastrophic childhood diseases worldwide. With both science and patient care on one campus, St. Jude is the epicenter of pediatric cancer research and a unique resource for the global medical community.

The corporate partners and their employees and customers, the celebrity friends, the long-time supporters and donors to St. Jude, and everyone who is moved during the *Thanks and Giving* campaign to learn about St. Jude and support the hospital—all are a significant part of raising awareness about the importance of the St. Jude mission.

"This is such an important service, to let parents throughout the United States know about the research and treatment that is conducted at St. Jude," says Joseph Laver, MD, St. Jude clinical director and executive vice president. "Every donation is a gift of hope to those parents." ●

How can I help?



Look for the *Thanks and Giving* magnifying glass logo this holiday season wherever you shop to support the patients of St. Jude. *Thanks and Giving* partners include CVS/pharmacy, Kmart, Kay Jewelers, Dick's Sporting Goods, Target, AutoZone and Williams-Sonoma, plus many more.

To learn more about the *Thanks and Giving* campaign, visit www.stjude.org. You'll find a full list of *Thanks and Giving* partners, with details about where to shop and how to donate. You can also find out how to get involved in *I give my voice*, *my vision* or *my energy*. And you can meet some of the incredible children who are patients of St. Jude and learn about the hospital's groundbreaking research and world-class treatment.

Help Wanted

Exclusive night club seeks assistant for gullible bouncer. Candidate should be equipped to spot troublemakers and turn them away. Duties include knowing when to call for back-up to help keep out riffraff and poseurs.

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— BY MARY C. POWERS —

IF THE BRAIN housed an exclusive night club, the facility would likely be in the market for a new bouncer.

A recent study led by St. Jude Children's Research Hospital scientists found that a cell surface molecule the brain relies on to act like a bouncer—turning away bacteria and other threats—is easily duped.

That molecule is the laminin receptor (LR). Instead of protecting the brain by helping cells maintain a tight seal around it, the LR may be tricked by infectious agents. When the LR opens the door and provides a path into the brain, these agents make themselves at home, often with devastating results.

Enter Elaine Tuomanen, MD, St. Jude Infectious Diseases chair. She and her colleagues recently discovered that the LR plays a pivotal role in nearly all cases of bacterial

meningitis. When trying to infect the brain, other agents, including viruses, prions and poisons secreted by the *E.coli* bacteria, also target the LR.

In search of sidekicks

Tuomanen's group wants to give LR some help, possibly sidekicks better equipped to spot troublemakers and turn them away. In this case, the sidekick might be a vaccine to spark production of an immune system component known as an antibody. Antibodies are part of the body's front-line defense against disease.

"If you can block the door, you will block a lot of disease-causing organisms of the brain," Tuomanen explains. She and her team have detailed LR's role in allowing three bacteria responsible for nearly all bacterial meningitis to infiltrate the brain.

Bacterial meningitis is an inflammation of the membrane covering the brain and spinal cord. Once bacteria enter the cerebrospinal fluid bathing the brain and spine, they multiply rapidly. The resulting inflammation kills 30 percent of patients and leaves some survivors with devastating brain damage.

Tuomanen has devoted her professional life to combating one of the leading causes of bacterial meningitis, a bug known as *Streptococcus pneumoniae*. The microorganism enters the body through the nose. From there, pneumococcus sometimes moves on to infect the lungs, blood and brain, leaving pneumonia, ear infections, other illnesses and even death in its wake. Although vaccines are available against the most common types of the pneumococcus, the

bacterium still kills as many as 1 million individuals every year, mostly young children living in developing countries.

Interviewing candidates

Along with deciphering how pneumococcus and other bacteria invade the brain, Tuomanen guides St. Jude involvement in an international coalition working to develop a safe, affordable, protein-based vaccine effective against all of the 90-plus strains of pneumococcus. Known as the Pneumococcus Vaccine Consortium, the group began work in earnest in 2007 and has attracted leading scientists from industry, academic and research centers plus support from PATH, an international nonprofit group based in Washington D.C. PATH is short for Program for Appropriate Technology in Health.

The cooperative effort has already generated more than a dozen potential vaccines now being tested in

laboratory models. Within a year, the most promising will likely be ready for human trials.

St. Jude scientists have not only supplied vaccine candidates, but also made all the consortium's experimental vaccines. That work was done in the hospital's Protein Production Facility. Available to all St. Jude faculty, this facility is designed to help speed translation of scientific discoveries into better medical care.

As the consortium's work moves to human trials, those experimental vaccines will be made in the Children's GMP, LLC. The Good Manufacturing Practices (GMP) facility operates under government-approved manufacturing guidelines and produces the highly specialized medicines and vaccines that pharmaceutical companies are reluctant to pursue.

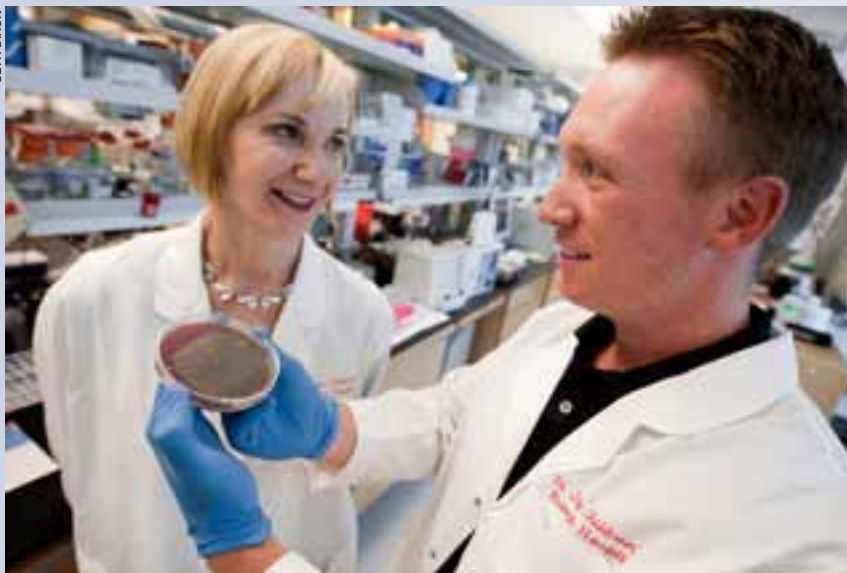
"To have the Protein Production Facility and the GMP facility on

campus makes St. Jude unique in the world of medical science," Tuomanen says. "There is no one out there who will make new vaccines for children. It is too hard and too expensive. We are in a position to make this difference. No one else has this capability. It is a perfect match to the St. Jude mission."

Even as researchers push ahead with efforts to produce a universal pneumococcal vaccine, Tuomanen sees an exciting opportunity to broaden vaccine protection against bacterial meningitis by studying LR. Tuomanen and her colleagues recently found that the three bacteria responsible for nearly all bacterial meningitis begin their assault on the brain at LR. Pneumococcus, *Neisseria meningitides* and *Haemophilus influenza* use different proteins to adhere to LR. But once they do, researchers report a biochemical cascade begins. The end result is meningitis.

"The findings suggest there is a common way to stop the bacteria responsible for the most common forms of meningitis," Tuomanen explained. LR is a good place to start. ●

"If you can block the door, you will block a lot of disease-causing organisms of the brain."



Elaine Tuomanen, MD, Infectious Diseases chair, and Justin Thornton, PhD, postdoctoral fellow, Infectious Diseases, examine a plate of pneumococcus in the lab. The bacterium kills as many as 1 million individuals every year, mostly young children living in developing countries. Tuomanen spearheads the hospital's involvement in an international coalition working to develop a vaccine effective against all of the 90-plus strains of pneumococcus.

Putting FaMiLY at the Center

Family-centered care gives St. Jude families an active role in decision-making.

BY SUMMER FREEMAN



PETER BARTA

St. Jude patient Sam Farris (center) recently helped the hospital create family-friendly directional signs during a renovation of patient care areas. He discusses that project with (from left) Family-centered Care Coordinator Alicia Huettel, RN; Family-centered Care Assistant Pamela Priester; and Sam's mom, Teresa Farris, Family Advisory Council member.

When coming to St. Jude Children's Research Hospital, each parent grapples with challenges regarding medications, medical procedures and boo boos that cannot be kissed away. For the parents of children who are battling devastating diseases, so much is out of their control.

But thanks to the hospital's philosophy of family-centered care, parents and their children are given a voice and a sense of control during an arduous time.

"As parents, our mission is to take care of our kids. We lose such control when we walk through the hospital's doors—not to the doctors, but to the disease," says St. Jude parent Heather Durham. "To be able to say something about how your child is cared for is paramount. Being asked whether my son wanted blue Jell-O or red Jell-O may seem very small, but it meant a lot that I had a voice in his daily care."

Counseled by the council

Family-centered care extends far beyond dessert preference. It is an approach to care that seeks answers to the direct needs of patients and their parents by asking them for input and responding in kind.

"It is about respecting the unique relationship that the family has with the health care team and validating the strengths that each family brings to the hospital when their child is ill," says Alicia Huettel, RN, St. Jude family-centered care coordinator. "In a traditional health care delivery model, the system—whether it is the physicians, nurses or other staff—has been what dictates care. Family-centered care is different in that it puts the family at the center of decision-making, empowers them and honors their preferences."

Huettel says that this philosophy has always existed at the heart of St. Jude, but now health care workers nationwide are putting a name to it and finding new ways to evolve and advance this mission.

To help nurture this approach to care, the hospital established the Family Advisory Council. Family members of patients hold two-thirds of the seats on the committee, and faculty and staff from hospital departments make up the remaining spots. Durham serves as chair of the group.

Through the council, hospital employees meet with parents and patients to discuss an array of topics that affect patient care from construction projects to the way the pharmacy provides medicines to patients after hospital discharge. "The process creates pathways of information and communication," Huettel says. "We're getting their input on the front end, discussing options and making decisions together."

John Curran, director of St. Jude Design and Construction, says the council provides a helpful sounding board. "We don't want to build things that parents don't want," Curran says of the group's feedback. "Before the council, we formed focus groups of parents and patients to discuss projects whenever we could, but now we are getting consistent input by working as a team."

When Curran and his team were creating new campus maps, he presented them to the council. "They offered insight on how to make them more readable," he says. "They know what it's like to be parents who are trying to find their way around the hospital for the first time."

A fresh outlook

Heather Durham says parents can offer a fresh set of eyes on day-to-day life at St. Jude that might not be seen by hospital employees.

"The response of the nurses, doctors and other staff that we've met with has been amazing," she says. "They are thirsty for our opinion—even when it is something as small as 'Add memo pads in the rooms for parents to write down their questions while they are waiting for the doctors.' By sharing these real-life experiences that parents have each day, we help make everyone's time at St. Jude a little better."

St. Jude parent and Family Advisory Council member Teresa Farris agrees. "Communicating and understanding our family's journey extends to after therapy has ended as well, and family-centered care supports us as we continue on this path," she says.

Huettel and her team employ several tactics for sparking dialogue between families and health care workers. Parents serve as active members of various hospital committees. Focus groups are held to obtain the input and opinions of parents and patients. An informational newsletter is also published each month to address topics most pressing to St. Jude parents.

In addition to reaching out to parents for feedback, Huettel and her team look for ways to strengthen the initiative by inviting evaluators to assess the program as well as by holding advanced training and seminars for hospital staff.

"The idea of putting the family at the center of care is not new to St. Jude, but now we're putting actions to the philosophy and finding ways to move it forward," Huettel says. "There is a business case for it, because including parents in the decision-making on the front end increases satisfaction as well as improves quality and safety. But more than anything, we've embraced the family-centered care approach because it's the right thing to do." ●



ALL: Survive and Thrive

St. Jude clinicians announce the best survival rates ever reported for ALL. What could be better than that? Achieving those rates without the use of cranial irradiation.

BY ELIZABETH JANE WALKER

As part of his job as a neonatologist, Venkat Kakkilaya, MD, sometimes has to share bad news with families. It's never a pleasant experience. But he recently encountered a much more daunting task: informing his wife, Hema, that their son had acute lymphoblastic leukemia (ALL), a cancer of the white blood cells.

"Telling Hema was not easy," he recalls. "It was a very traumatic day. The worst day in my life, I would say."

But when the family arrived

at St. Jude Children's Research Hospital, Oncology Chair Ching-Hon Pui, MD, shared some encouraging news. Eleven-year-old Akash would receive a carefully personalized chemotherapy regimen to combat his disease. And—unlike countless children who have been treated for ALL in the past and many being treated to date worldwide—Akash would not have to undergo cranial irradiation as part of that therapy.

Earlier this year, Pui and his St. Jude colleagues established that children who receive personalized

chemotherapy treatments actually enjoy better outcomes than children who receive a combination of chemotherapy and cranial irradiation. In the *New England Journal of Medicine*, the researchers announced that they had achieved the highest cure rates ever for ALL.

"This is the first study that proves that with effective chemotherapy, cranial irradiation can be totally omitted in all children with ALL," says Pui, an American Cancer Society professor.

Akash Kakkilaya is one of many

Ching-Hon Pui, MD, Oncology chair, talks with 11-year-old Akash Kakkilaya during a checkup for acute lymphoblastic leukemia. Pui and his colleagues recently announced a five-year survival rate of 94 percent for children with ALL.

children who are reaping the benefits of that research.

Early triumphs

To understand implications of this study, rewind to 1962—the year the Beatles released their first hit, John Glenn orbited Earth and St. Jude opened its doors. The outlook for children with ALL was grim; 96 percent would not survive their disease. Chemotherapy for ALL was in its infancy. Remissions—when they occurred—were typically brief.

St. Jude clinicians soon noticed that many of the children who achieved remission died after cancer cells reappeared in the fluid surrounding their brains and spinal cords. When St. Jude began administering preventive radiation to the cranium and spine, the cure rate jumped to 50 percent.

“This was one of the biggest single gains in anti-tumor effectiveness that has ever been seen,” observes Mary Relling, PharmD, St. Jude Pharmaceutical Sciences chair.

For a while, nearly every child with leukemia received radiation to the brain and spinal column. But the side effects were harsh: learning deficits, hormone imbalances and a high risk of second cancers.

Since the 1970s, clinicians have sought to reduce the amount of radiation necessary to achieve cures. In recent years, many institutions have used cranial irradiation only on children who demonstrated the highest risk of central nervous system (CNS) relapse. According to Pui, about 20 percent of patients with high-risk leukemia currently receive preventive cranial irradiation each year in other U.S. institutions. In some developing countries, clinicians

continue to use radiation treatments for most children with ALL.

“It has been a judgment call among different centers about whether they are willing to put up with the increased risk of late side effects in order to have a higher antileukemic effect,” Relling says. “Obviously we think that it’s not worth the risks.”

To individuals who question whether St. Jude is correct in removing radiation from ALL treatment, Pui’s answer is succinct: “No patients have died of CNS relapse in the past decade at our center.”

A new look at old drugs

To obtain the latest survival rates, the researchers designed a protocol featuring drugs that have been a part of the ALL treatment arsenal for years.

“There haven’t been that many new drugs for ALL introduced in the past few decades, but our ability to select and dose the ones we currently have has improved tremendously,” explains William E. Evans, PharmD, St. Jude director and CEO.

The new study used 11 anticancer drugs. Some medicines were infused directly into the spinal cord, while others were administered into the bloodstream. Investigators tailored treatment based on each child’s genetic make-up and how that patient metabolized, absorbed, excreted and responded to the drugs.

Investigators modified therapy based on a test performed in the lab of Dario Campana, MD, PhD, Oncology. The minimal residual disease or MRD test detects even the smallest number of leukemia cells that remain after the first six weeks of chemotherapy.

“Parts of this regimen have been used by other groups, but it has never been used in exactly this cocktail,” Relling says.

Sharing the good news

Children in the St. Jude study enjoyed a five-year survival rate of 94 percent and a projected 10-year cure rate of 90 percent. Plus, their quality of life should be better because of the absence of radiation treatments. Indeed, early neuropsychologic testing showed that survivors of the study have normal intelligence as compared to the normal population.

“The five-year survival rate in the U.S. and in Western Europe (with the use of radiation) is approximately 85 to 90 percent,” Pui explains. “The rates in other parts of the world are lower.”

Is it possible for other cancer centers to replicate these results? St. Jude researchers respond with an enthusiastic “yes.”

“Now that we have shown that it works, anybody at a major academic medical center should be able to implement this,” Evans says. “Of course, that’s what St. Jude does—we focus on research and then share it with the intent of impacting the care of kids who never come on our campus. When we are pushing the cure rates this high, that’s terrific news for families.”

It’s also terrific news for Akash Kakkilaya, who does not have to worry about the learning deficits caused by cranial irradiation. Instead, this sixth grader who excels in science and math anticipates the day when he can return home to participate in all of his regular activities—cured of ALL. ●

A Step in the *Right Direction*

St. Jude steers tiny DJ Pete onto the right path after a series of life-threatening medical setbacks.

BY MIKE O'KELLY

Peering over eyeglasses that rest on cheeks as pinchable as tufts of cotton candy, Douglas “DJ” Pete Jr. aptly deserves his nickname, “the little professor.” The moniker not only applies to DJ’s appearance but also to his life story, as he has seen and experienced far more than most toddlers.

DJ is not a typical toddler because, at 21 months of age, he has yet to take his first step. But with the help of clinical staff and occupational and physical therapists at St. Jude Children’s Research Hospital, he should soon be able to stride from the steady arms of his father, Doug, into the embrace of his mother, Shana.

Born with Down syndrome, DJ has endured surgery to repair three holes in his heart and is currently battling acute myeloid leukemia (AML)—the illness that

brought him to St. Jude earlier this year.

A stumbling block

Shana Robinson had no reason to suspect that her pregnancy with DJ was anything but normal. A prenatal blood test for Down syndrome had come back negative. But shortly after DJ’s birth a newborn screening revealed that he had the genetic disorder.

“It was a shock,” Shana says. “I knew what Down was, and DJ didn’t have any features. But doctors pointed out the slight bridge on his nose, the gap between his toes and a folded ear.” Those characteristics are indications of Down syndrome. Because this disorder is caused by the presence of all or part of a third 21st chromosome, the syndrome is also called trisomy 21.

Children with Down syndrome are at risk for other medical con-

ditions, including heart problems. A cardiologist discovered a minor heart murmur in the newborn and told Shana to return for a checkup in 90 days. But a month later, she and Doug rushed DJ to the emergency room after he stopped eating and his breathing became shallow. He was experiencing congestive heart failure.

At the hospital, an echocardiogram revealed several holes in DJ’s heart. He received medication to prevent the holes from enlarging and underwent surgery.

“They repaired all three holes, but by the time we returned home and did a follow-up with the heart doctor, one of them was back open,” Shana says. “It was a small hole that will end up closing on its own.”

Unforeseen obstacles

For the next year, life seemed to return to normal. Then in January 2009, DJ exhibited worrisome cold



DJ Pete acquires new skills as he plays with toys under the watchful eye of St. Jude Rehabilitation Services staff. During his treatment for acute myeloid leukemia, DJ has received regular sessions of speech, physical and occupational therapy. As a result, he has begun to reach many developmental milestones.

symptoms. Tests showed that he had a respiratory virus, a low number of infection-fighting white blood cells called neutrophils and a low platelet count. When a follow-up visit revealed another low platelet count, a hematologist biopsied DJ's bone marrow to test for leukemia.

The biopsy showed that DJ had 5 percent blast cells in his bone marrow. Blast cells are immature cells that do not develop into normal red or white blood cells or platelets.

Normally, blast cells make up less than 5 percent of all cells in the marrow. An increase to 5 percent or more indicates myelodysplastic syndrome (MDS). In MDS, the bone marrow produces improperly functioning blood cells that may develop into leukemia cells. People with more than 20 percent blast cells are considered to have AML, which is leukemic infiltration of the bone marrow.

The replacement of normal bone

marrow cells with leukemic cells usually causes fever, pallor, fatigue, abnormal bleeding and bone pain. Although DJ was not exhibiting the typical symptoms, he was referred to St. Jude for further evaluation. Shana, who had never flown before, boarded a plane with DJ for the flight from Louisiana to Tennessee.

"My family drove me to the airport, and I was just terrified," Shana says. "We had already been through so much that we thought there can't possibly be anything else that could happen."

Shana and DJ arrived at St. Jude February 19, 2009, one year to the day after his heart surgery. Immediate testing revealed that his blast cells had reached 22 percent. DJ was found to have a rare subtype of AML, acute megakaryoblastic leukemia—also known as AMKL or AML M7.

A rare condition

According to Piya Rujkijyanont, MD, of St. Jude Oncology, leukemia occurs 10-to-20-fold more frequently in patients with Down syndrome than in patients in the general population. Yet, the incidence of solid tumors is approximately half that of the general population.

"The higher incidence of leukemia is likely from genetic factors related to Down syndrome, including genetic instability caused by trisomy 21," says Rujkijyanont, DJ's postdoctoral fellow. "The explanation for the lower incidence of solid tumors remains uncertain."

Although AML M7 is extremely rare in the general population, two-thirds of children with Down syndrome and AML are found to have this type.

Clinicians enrolled DJ in a protocol developed specifically for children with Down syndrome and AML or MDS. After having received six rounds of chemotherapy,

Oncologist Piya Rujkijyanont, MD, greets Shana and DJ during a recent checkup. At St. Jude, DJ was enrolled in a protocol developed specifically for children with Down syndrome and acute myeloid leukemia or myelodysplastic syndrome.



his most recent bone marrow evaluation reveals no evidence of leukemia.

Back on track

During his treatment, DJ has been undergoing speech, physical and occupational therapy sessions in the St. Jude Rehabilitation Services department. Because children with Down syndrome tend to have lower muscle tone, most of them lag behind the norm in achieving developmental milestones, such as speaking, crawling and walking. This limits even basic actions like handling and picking up toys. DJ's first interaction with toys involved uncontrolled hand-slinging, which resulted in the random tossing of toys.

"Motor development begins near the body and extends out to the limbs," explains St. Jude occupational therapist Jessica Allen, who initially concentrated on building DJ's core strength in his abs and back.

When DJ arrived at St. Jude, he would plop forward with his arms and prop himself up to sit. As his strength increased, DJ began to sit up on his own and even began to crawl. This led to greater use of his hands and eventually interaction with toys, resulting in normal play.

Children with Down syndrome can also be over-stimulated and fearful of certain textures, colors or sounds. "We worked a lot with DJ on sensory-integration activities where we provide stimulation to him at a

level he can tolerate," Allen says. "We work up to where he becomes more tolerant not only of different sounds and textures but also of moving in different ways."

Before interacting with Rehabilitation Services staff, DJ was afraid to stand. But by participating in motion activities like rocking and swinging, he has reached another milestone by standing. His speech has also improved, and he is now more willing to interact with people.

"He's starting to say some words and imitate sounds," Allen says.

The road ahead

Now that DJ's chemotherapy treatment is coming to an end, he will soon be returning home to begin early-intervention services for his rehabilitation. With all the experience and education the family has gleaned in the medical field throughout DJ's journey, Shana is now interested in attending nursing school and Doug is considering a career as a radiology technician. Both are grateful for what St. Jude has done for DJ.

"We want to do something with this experience by helping somebody else," Shana says. "I realize now how many people donate to St. Jude. After this, we're going to donate. They helped me out so much, so now I can give back." ●

Down Syndrome and Leukemia

Children with Down syndrome have a 10-to-20 times higher risk of having leukemia than do children in the general population. On the other hand, their risk of having a solid tumor is much lower—the incidence is approximately half that of the general population. Most children with Down syndrome have three copies of chromosome 21 in every cell of their body. The extra genetic material may contribute to the onset of leukemia.

At St. Jude, DJ is enrolled in a protocol specifically for the treatment of children who have Down syndrome, acute myeloid leukemia (AML) or myelodysplastic syndrome (MDS). Children with AML usually receive treatment consisting of intensive chemotherapy and stem cell transplantation. However, patients with AML and Down syndrome have leukemia blasts that are extremely sensitive to chemotherapy. For that reason, these children receive moderate-intensity chemotherapy without undergoing transplants.

The St. Jude **ICU:** *In Good Hands*

BY JOYCE M. WEBB

In a unique ICU devoted solely to pediatric hematology/oncology patients, dedicated employees care for the hospital's most vulnerable children.

Julie Huggins, RN, pumps a dollop of hand sanitizer into her palms and gives them a brisk rub. By the time the cool tingle fades, her gloves and gown are intact for the start of her 12-hour shift in the Intensive Care Unit (ICU) at St. Jude Children's Research Hospital.

She and the staff of nearly 70, including physicians, staff nurses, nurse leaders, nursing care assistants, health unit coordinators and respiratory therapists, provide

lifesaving care to more than 300 patients admitted each year to the eight-bed unit—a unique ICU devoted solely to pediatric hematology/oncology patients.

Members of the ICU staff are not immune to the demands of the job, and some say they would be wealthy and retired if they collected a dollar for each time someone asked, “How do you do it?”

“It gets emotional at times because I have two small children of my own,” Huggins says. “I find myself

PHOTOS BY SETH DIXON



To provide the best possible care, St. Jude offers a staffing model unmatched in most ICUs: a 1-to-1 nurse-to-patient ratio; 2 to 1 when treating the most severe cases.

complaining about getting up in the middle of the night because my 3-month-old is fussy, but that's small compared to what these families are going through."

Matching the critical need

An impressive nurse-to-patient ratio, staff longevity and improved patient outcomes from best practices in critical care are hallmarks of the St. Jude ICU.

Because of their weakened immune systems from treatment for cancer and other catastrophic diseases, St. Jude patients are at high risk for developing life-threatening infections that require a higher level of care. In the ICU, the critical care team administers antibiotic and fluid therapy and provides 24-hour monitoring to prevent the spread and severity of infections. In some cases, patients require life-supportive services such as mechanical ventilators, renal replacement therapy or other high-level, multi-organ support.

To provide the best possible care, St. Jude offers a staffing model unmatched in most ICUs: a 1-to-1 nurse-to-patient ratio; 2 to 1 when treating the most severe cases.

"Long ago the St. Jude leadership decided that the acuity for these children with cancer is high enough to staff at these ratios in order to provide optimal care for our patients," says Ray Morrison, MD, St. Jude Critical Care Division chief. "Our ability to staff at a level that gives us a dedicated nurse educator and clinical nurse specialist is essential to nurse retention, job satisfaction

and the ability to involve them in critical care at a level that's commensurate with their expertise."

The model also underscores the longevity in the St. Jude ICU. Many employees tally their service in double digits. For instance, Michelle Mosby, RN, and Barbara Taylor, RN, have each devoted more than 30 years to St. Jude patients with critical care needs.

"This job is not cut out for everybody," Taylor says. "I've served in several nursing leadership roles and have worked on all shifts. I love bedside critical care nursing and using the technology to provide the best care for our patients."

Partners in the journey

The ICU staff is sensitive to the uncertain journey that families face during treatment.

"When children are sick, many times parents feel as if they have lost control of caring for their own children. So we partner with them in decision-making and honor family preferences, which is the essence of family-centered care," says Nan Henderson, RN, an ICU nurse manager. "This gives parents that sense of control back at a time when they feel like there's nothing they can do to make things better."

A sign hangs on a wall near the nurses' station celebrating those caught in the act of caring. This exceptional care has been recognized internally and in the larger medical community.

The nursing staff recently received the prestigious

Aubrey Lamptey, MD (left), and Ray Morrison, MD, St. Jude Critical Care Division chief, are among the few critical care physicians nationwide who specialize in pediatric oncology.





St. Jude ICU nurses, including Alexis Maestri, RN (left), and 31-year veteran Michelle Mosby, RN, have been nationally recognized for excellence in critical care.

Beacon Award for Critical Care Excellence from the American Association of Critical-Care Nurses. Less than 3 percent of the estimated 6,000 ICUs nationally have received the honor. Most recently, the critical care team was recognized among peers at St. Jude with the Outstanding Clinical Care Improvement Award for significantly improving clinical infrastructure to support the hospital's mission.

Even these accolades pale in comparison to the greatest reward they receive when they witness miracles in the unit.

Witnesses to miracles

Barbara Robinson, RN, a St. Jude critical care nurse for 16 years, recalls many times when children facing the gravest situations beat the odds.

"I once worked in an adult ICU and saw many of them face end-of-life issues, but it's different when children face the same prognosis," she says. "Coming to St. Jude really opened my eyes. The families are grateful, and the children—many of whom are wise beyond their years—have taught me to appreciate life..."

Before Robinson can continue, an impromptu visit from a 2-year-old underscores the miracles that occur in the ICU. The boy once spent six months in the unit. Now in remission from a stage IV brain tumor, the child and his parent visit the team between clinical appointments.

Pheraby Witham, RN, remembers the early years of critical care when children who received mechanical ventilation after undergoing bone marrow transplantation had a survival rate of less than 1 percent. Many children were not admitted to ICUs because further treatment was deemed futile.

"St. Jude physicians continued trying regardless of the odds," Witham says. "I remember caring for one patient who was in that less-than-1-percent category. Years later, he ended up being my waiter at a local restaurant. I've seen miracles many times when others

said there was no way that these children would survive."

With improvements in critical care medicine, many St. Jude patients in ICU now experience long-term survival.

Pass it on

The ICU nurses share their expertise by participating in clinical studies, implementing practices that improve patient outcomes and publishing their findings in leading nursing journals.

"Much of the existing literature is not geared toward our unique patient population," explains Yvonne Avent, RN, clinical nurse specialist. "So we review practices in general pediatrics and adult care that have been proven to work, modify them to fit our patient population and monitor our progress."

Current critical care research includes evaluating outcomes of two diagnostic procedures to examine lung infectious processes in leukemia patients and evaluating the effect that the hospital's Rapid Response Team has on ICU patient outcomes.

"The Critical Care Division works closely with nursing to evaluate outcomes for children we have discharged, for patients who received and later came off of mechanical ventilators, and for patients who have had critical events," Avent says. "Our data show that we've done very well in all of these areas."

As St. Jude continues to help set the worldwide standard for pediatric critical care medicine, one ICU veteran plans to devote several more years to the journey.

"To see the many changes and successful patient outcomes that have taken place over the years is truly amazing," says Barbara Taylor, who has worked in the unit for 36 years. "People always ask me when I plan to retire, and I say, 'Ooh—not for another eight to 10 years.'" ●

Perspective

BY SEAN SWARNER

Keep Climbing

The first cancer survivor to summit Mt. Everest offers motivation to St. Jude survivors and supporters.



At age 13, I was diagnosed with Hodgkin lymphoma; at 16, Askin sarcoma. In high school, I was known as “cancer boy”—this infected kid who was given 14 days to live. Despite the rigorous chemotherapy treatments, weight gain, hair loss and eventually having only one fully functioning lung, I survived. I went to college and thought I had left all that behind.

When I started graduate school, I began to look at my life and what it meant to me. I was a thousand miles away from my family and friends and from anyone who knew I had even had cancer. I realized that being affected by this disease did not necessarily define who I was, but actually helped me become who I was. I realized that life is fragile; life is short; life is precious.

Taking this newfound encouragement, I was more

motivated than ever to show cancer survivors and others that we have a responsibility to give back to current patients, to do our part and to spread hope.

One of my other nicknames was “nature boy” because I loved climbing and being outside. I wanted to reach out and make a difference in the lives of people touched by cancer. I wanted—literally—the highest platform in the world to give them hope.

On May 16, 2002, I became the first cancer survivor to summit Mt. Everest, the world’s highest peak. I’ve since summited Kilimanjaro, Denali, Elbrus, Aconcagua, Carstensz Pyramid and Vinson, also known as the seven summits (the highest mountain on each continent).

I started sharing my story. My whole life journey is about hope. What keeps me going is helping kids and adults with cancer, helping the parents of those kids—the doctors, the nurses, the caregivers, the families.

Touring St. Jude Children’s Research Hospital for the first time, I thought it was a fantastic facility. Having cancer can be traumatic; it becomes part of your life. St. Jude and other places that promote hope are what keep me going and speaking


and never giving up. When I spoke to childhood cancer survivors at St. Jude a couple of years ago, I found myself in a community of people who work hard every day to continue that feeling of hope and motivation.

Climbing these peaks and speaking to people—from cancer survivors to anyone who has been touched by cancer—has allowed me to go around the world and give even more people hope. It reiterates the importance of supporting places like St. Jude and people who have been touched by cancer. I am having fun with my life. Never give up, and never lose hope.

Sean Swarner is a cancer survivor, motivational speaker, the author of Keep Climbing and competitor in the 2008 Ironman World Championship. He has his sites set on trekking to the North and South Poles.



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**Laughter is the
best medicine**

Robin Williams cuts up with St. Jude patient Ben Sherman during the taping of a commercial for this year's *Thanks and Giving* campaign. Look for the *Thanks and Giving* magnifying glass logo this holiday season wherever you shop to support St. Jude research and treatment. See page 6 for more details on this year's campaign.

PETER BARTIA



Finding cures. Saving children.