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

Promise

Autumn 2004

Marlo Thomas Launches Thanks & Giving

Finding cures. Saving children.

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

332 N. Lauderdale St.
Memphis, Tennessee 38105-2794

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

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

Promise.

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

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

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ALSAC National Executive Director
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Promise

A publication of St. Jude Children's Research Hospital Autumn 2004

Features

Highlights

Perspective

On the cover: Marlo Thomas and St. Jude patients generate excitement for Thanks & Giving. (see article, page 10). Photo by Biomedical Communications.

Highlights

New director

St. Jude enters a new era in November, as William Evans, PharmD, becomes the hospital's director. A longtime St. Jude employee, he has served as deputy director, scientific director and Pharmaceutical Sciences chair. Evans will succeed Arthur Nienhuis, MD, who held the position for 11 years. After a yearlong sabbatical, Nienhuis will work full time on his Experimental Hematology research program at St. Jude. Evans has the unique distinction of having worked under all four of his predecessors—Donald Pinkel, MD; Alvin Mauer, MD; Joseph Simone, MD; and Nienhuis.

Sherr winner

Charles Sherr, MD, PhD, Herrick Foundation chair of Genetics and Tumor Cell Biology at St. Jude and an investigator of the Howard Hughes Medical Institute, has been awarded the Charles S. Mott Prize by the General Motors Cancer Research Foundation. The Mott Prize has been bestowed on a select number of the world's top scientists, 11 of whom have subsequently won Nobel Prizes. Sherr was cited for the discovery and characterization of key genes and proteins that control cell division and that are frequently involved in the development of cancer.

Breaking ground

In August, St. Jude began construction of a 300,000-square-foot facility that will expand the institution's Radiological Sciences and Brain Tumor programs. The six-story Integrated Patient Care and Research Building will include two floors for Radiation Oncology and Diagnostic Imaging, plus four floors that will eventually be used for patient care and laboratories. The building is expected to be completed in March 2007. *(See related photo, inside back cover of this issue.)*

The Integrated Patient Care and Research Building

Drug offers hope

St. Jude investigators have discovered that children whose acute lymphoblastic leukemia returned after initial treatment or was unresponsive to other therapies had a 31 percent overall response rate to the investigational drug clofarabine. A number of children with refractory or relapsed acute myeloid leukemia treated with the drug also went on to receive bone marrow or stem cell transplants. A New Drug Application for clofarabine has been submitted to the U.S. Food and Drug Administration. If granted FDA approval, it will be the first new pediatric leukemia drug to be made available exclusively to children in more than a decade.

St. Jude in Brazil

The city of Recife, Brazil, experienced a significant improvement in outcome among children treated for acute lymphoblastic leukemia (ALL) during the past decade, even though the community is resource-poor and most patient families are impoverished. These findings are published in the May 2004 *Journal of the American Medical Association* by physicians at St. Jude, who designed a program to improve ALL treatment in Recife.

Latest Pew Scholar

Michael Dyer, PhD, of St. Jude Developmental Neurobiology, is one of 15 biomedical scientists in the nation to be named a 2004 Pew Scholar. His research focuses on retinal development and the function of the retinoblastoma gene family. Brenda Schulman, PhD, of Structural Biology and Genetics and Tumor Cell Biology, became the hospital's first Pew Scholar in 2002.

High scores

The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) has begun publishing organization-specific performance reports on its Web site. St. Jude scored a 98 on its last JCAHO evaluation. To review the St. Jude quality report or that of any other JCAHO-accredited organization, visit *www.jcaho.org*.

Making news

St. Jude was featured in *U.S. News & World Report's* special "Best Hospitals in America" edition, published July 12, 2004. Every year *U.S. News & World Report* ranks the nation's top hospitals. The unique mission of St. Jude is broader than the scope of the magazine's predetermined categories. So this year, the publication highlighted the hospital's role as a leader in the battle against childhood cancers, its ability to move research discoveries from the bench to the bedside and the advancement of tailoring treatments.

For more news about St. Jude, visit *www.stjude.org/media.*

Dental Work

Taking care of teeth is all work and no play…except at St. Jude, where laughter and compassion merge with research and clinical care.

By Elizabeth Jane Walker

ANN-MARGARET HEDGES

Christopher Rowland, DDS, and his Dental Clinic colleagues play a major role in helping St. Jude patients avoid life-threatening infections and in dealing with the side effects of cancer treatment. But sometimes, laughter is the best medicine. For instance, during the hospital's Halloween festivities, Rowland joins in the fun.

In a secluded corner of St. Jude Children's Research Hospital, a patient howls with delight, a web of neon-colored Silly String streaming across his head and torso. "This is payback for a past visit when he ambushed me," laughs Dental Clinic employee Diana Hill, as the 14-year-old patient proudly displays his rubbery cape like a badge of honor.

Welcome to the St. Jude Dental Clinic, a place of laughter and hugs, smiles and jokes. But it's also a place where patients come for serious treatment and education that could literally save their lives.

In spite of a staff consisting of only three employees, the clinic is a hub of constant activity. Hill and her colleagues will perform about 5,043 procedures on nearly 900 patients this year, numbers that have tripled since 2001. But many people are unaware of the clinic's services.

"A lot of people don't realize the importance of what we do here," says Kathy Wortham, dental assistant. "They say, 'Can't the kids get their dental care at home?' Well, the answer is no."

Wortham says the requirements of patients at St. Jude extend far beyond the scope of most general dentists, who rarely treat children with cancer or sickle cell disease, HIV infections or genetic

disorders. “The abnormal is the normal here,” she says. “Out in private practice, you almost never see any of these abnormalities.”

Life-saving checkups

Although all St. Jude patients do not visit the Dental Clinic, many of them do as part of their protocols, or scientific treatment plans. Every child scheduled for a stem cell transplant must have a dental examination. During the transplant process, patients’ infection-fighting ability usually plummets. Christopher Rowland, DDS, says it’s imperative for these children to be as healthy as possible before they begin treatment.

“If kids go to transplant and have cavities or abscessed teeth, they could get terrible infections,” Rowland says, “and if they get infections, they could have serious complications. Why put kids at risk when all we have to do is do an exam?”

All patients undergoing head and neck radiation also visit the Dental Clinic. Radiation shuts down the salivary glands and puts these children at risk of developing cavities. Saliva normally bathes the teeth and washes away bacteria. But when saliva is absent, bacteria attack the teeth and cause them to deteriorate. In addition to daily, self-administered fluoride treatments, St. Jude patients undergoing head and neck radiation use toothpastes, mouthwashes and artificial saliva specifically formulated to alleviate the problems they encounter. “Without immaculate care, some of these kids are susceptible to serious problems,” Wortham says.

The Dental Clinic staff use humor to offer gentle correction to patients who balk at taking scrupulous care of their teeth. Today, a preteen from Dallas, Texas, admits he does not always floss or use fluoride. “I’m already using five different mouth rinses three times a day,” he complains.

“Well, that will keep you from getting mouth sores,” Wortham replies. “But if you want to keep your teeth, it’s really important to take care of them.

SETH DIXON

As Christopher Rowland, DDS (at left), works on the teeth of a patient, Geisa Silva, DDS, chief of the Dentistry division at Hospital Araújo Jorge in Goiás, Brazil, observes St. Jude techniques. Silva spent a month visiting the hospital through the St. Jude International Outreach Program. “I learned many things, and I saw different types of treatment,” says Silva, who plans to use tips she has gleaned from Rowland in her own practice.

“Only brush the teeth you want to keep,” Wortham continues. “So if you don’t want to keep these two right here, don’t brush those.” Moments later, laden with a bagful of licorice toothpaste and cool flossers in fluorescent colors, the grinning boy climbs out of the examination chair and gives Wortham a hearty hug.

Beyond clinic walls

On a sunny Tuesday morning, the small clinic buzzes with laughter and the chatter of patients, parents, employees, a pediatric dental resident and two visiting dental students. Rowland uses dental hygiene students, residents and fellows to help clinic employees conduct more research and treat more patients; these young professionals simultaneously obtain valuable work experience.

St. Jude nurses also help Rowland and his colleagues promote dental health. Many patients undergoing chemotherapy develop mucositis, which causes mouth and throat sores. Rowland enlists nurses to help educate patients about mouth care.

Geisa Silva, DDS, chief of the Dentistry division at Hospital Araújo Jorge in Goiás, Brazil, recently spent a month at St. Jude as a guest of its International Outreach Program. “I learned many things, and I saw different types of treatment,” says Silva, who plans to use Rowland’s techniques for educating patients.

“Once a month, Chris goes to nursing orientation and teaches new nurses how to do mouth care,” Silva adds. “He is the only dentist there, and in my hospital it’s just me. It will help me a lot to make this change.”

PHOTOS BY SETH DIXON

(Top) After undergoing a dental procedure, St. Jude patient Travis Parker chats with Kathy Wortham and Rowland.

Sue Kaste, DO, of Radiological Sciences collaborates with Rowland on a variety of studies. “These research projects are really exciting because they benefit kids worldwide,” Kaste says.

Sharing information

About 14 years ago, Sue Kaste, DO, of Radiological Sciences began collaborating with Ken Hopkins, DDS, who was the St. Jude dentist at that time. She and Hopkins subsequently published some of the benchmark papers outlining the dental problems of childhood cancer patients. When Rowland arrived at St. Jude in 2002, he began working with Kaste on many projects, often involving students from the University of Tennessee Health Science Center’s College of Dentistry.

“There’s not a lot in dental literature about kids being treated for cancer,” Rowland explains. “We have tons of information at St. Jude that needs to be shared. That’s really my motivation for doing research.”

The projects are varied in scope. A recent study addressed tooth development in children with Hurler’s syndrome, a rare genetic disorder. Another project involves hundreds of orthodontists who are providing researchers with information about dental problems they have encountered in childhood cancer survivors. Yet another study looks at dental changes in children who have undergone bone marrow transplants. And an orthodontic fellow has begun studying the correlation between dental development and bone ages. Chemotherapy and other treatments can drastically affect dental development; this study will give orthodontists crucial information so that they can take better care of their patients.

“These research projects are really exciting because they benefit kids worldwide,” Kaste says. “We have the opportunity and the resources to make it happen. I’m really committed to maxing out what we can do.”

A global mission

During a momentary lull in the morning’s activities, Rowland, Hill and a resident visit the hospital’s third floor to examine a 15-year-old boy from Chile. In a two-hour span they have also treated children from Egypt, Mexico, Venezuela and across the United States.

Rowland says he enjoys the variety inherent in his work and the depth of relationships he can form at St. Jude. “My wife and I originally wanted to go into the mission field, where we could spend time in an economically depressed area or another country,” he says. “The great thing about being at St. Jude is that I’m there. I’m all over the world every day: in Beirut one hour; in Jordan a few minutes later; in lower Arkansas or Louisiana or North Dakota the next hour. I have a unique opportunity to serve families who are facing suffering or death…to share with those families and pray with some of them and do things that are not normal for regular private dentistry.

“It’s not fun watching these families suffer. But when good things happen, or when parents have a peace about what’s going on, it’s an encouraging thing to me. It’s a privilege to be here.”

Throughout a long dental procedure, a teenaged patient grasps Wortham’s hand, as if for emotional support. Afterward, Wortham admits that her involvement with St. Jude patients and families feeds her soul.

“God puts us in a place for a reason,” she says. “I love these families, and it’s such a blessing to me to be here with them. Dentistry’s just a bonus.

“Yes, I go home crying sometimes, and yes, I go home laughing sometimes. But these patients and their families are the reason that every day I want to come back here.”●

DRUGS BY *Design*

ST. JUDE IS AT THE FOREFRONT OF A FIELD CALLED PHARMACOGENOMICS, WHICH IS MAKING INDIVIDUALIZED MEDICINE A REALITY. DISCOVERIES IN THIS EMERGING AREA COULD MEAN THE DIFFERENCE BETWEEN LIFE AND DEATH FOR MANY CHILDREN WITH CANCER AND OTHER DISEASES.

BY TANUJA COLETTA

Genes determine whose eyes will reflect deep pools of mahogany and whose will shimmer like the sea. Sometimes these DNA segments give bragging rights to kids who've inherited the ability to roll their tongues. Yet, genes can also determine which children will develop deadly diseases like cancer and how these young patients will respond to potentially toxic medicines. Unfortunately, without knowing which genes are involved in drug response, predicting how someone will react to certain treatments has been a difficult, if not impossible, task — until now.

Medical revolution

Scientists at St. Jude Children's Research Hospital are using computer technology and new information about human genes to learn why some children with leukemia can be cured with few side effects while others reap no benefit from identical medications. This emerging field of science called pharmacogenomics could someday allow doctors to use genetic snapshots to determine how each patient will process drugs and how to adjust dosages accordingly.

St. Jude investigators William Evans, PharmD, and Mary Relling, PharmD, are leading some of the world's first pharmacogenomic studies in children with acute lymphoblastic leukemia (ALL). They hope that individualized medicine will eventually boost ALL's 80 percent cure rate closer to 100 percent, with children experiencing little or no side effects.

"Ultimately, we want to see drugs used in the most effective way—less toxicity and more efficacy," says Evans, hospital director-elect and member of Pharmaceutical Sciences.

Although researchers at other institutions now recognize that genetic testing has the potential to revolutionize medicine, Evans and Relling foresaw the benefits almost two decades ago when they opened the first pharmacogenomics research plan for St. Jude patients. "At the time, there were people doing similar research in adults with other diseases, but not for pediatric cancer," says Relling, Pharmaceutical Sciences chair. "In fact, few people were doing pharmacogenomic studies in cancer at all."

St. Jude has integrated pharmacogenomic studies in most of its primary and secondary clinical treatment plans. However, Evans and Relling say a medical revolution will occur only after researchers conduct more studies, develop more diagnostic tools and work with lawmakers to ensure patients' genetic information is not misused.

Goodbye to guesswork

Although more sophisticated than the "take two aspirin and call me in the morning" approach, the current science of selecting and dosing medications largely relies on trial and error, says Evans.

"You see what happens when you give a drug to 1,000 adults and come up with an average dose that you give almost everyone," he says. "This in essence treats every patient as if he or she were the average patient, when of course, few people are."

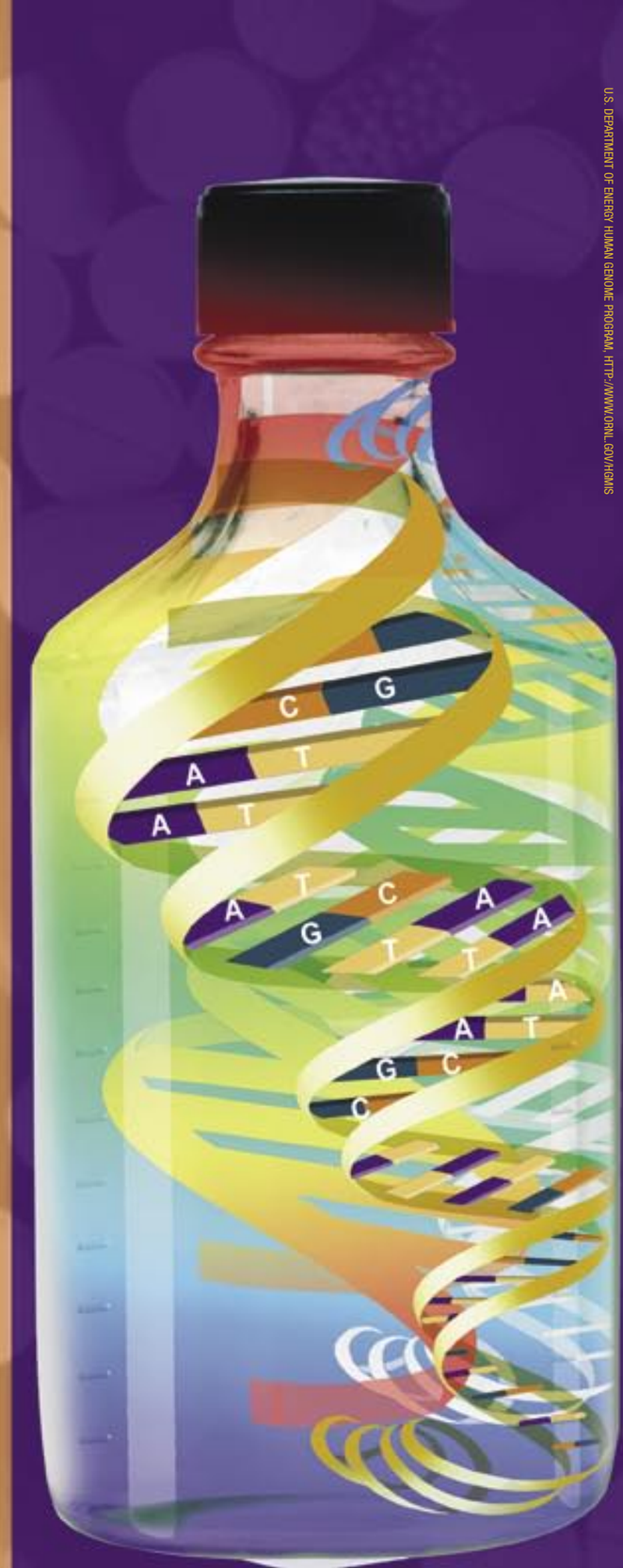
For a condition like high blood pressure, a doctor typically begins treatment with one of 10 drugs and adds, subtracts or switches medications based on patient reaction.

"With pharmacogenomics, a patient's genes could tell you exactly which drug is likely to work best," Evans says. "You might start with a completely different drug for the next patient."

For decades, doctors have collected patients' family medical histories as a surrogate for genetic tests. Pharmacogenomics uses a patient's genome to provide a more precise report on the drug response that has been inherited from their parents.

By taking the guesswork out of finding successful medications, pharmacogenomics could speed recovery times, expose new targets for medications and lower health care costs—curbing the likelihood of adverse drug reactions, which account for 100,000 deaths and 2.2 million hospitalizations in the United States each year.

For children with leukemia, it could mean that the harshest treatments are reserved for only those whose bodies can tolerate them and whose diseases need them. For some St. Jude patients, this has meant the difference between life and death.



U.S. DEPARTMENT OF ENERGY HUMAN GENOME PROGRAM, HTTP://WWW.ORNL.GOV/HGMIS

Put to the test

Eight months after Cassidie Jackson was born, her parents, Latisha and Brandon, noticed their daughter's lymph nodes felt like knots around her neck. They arrived at St. Jude, where doctors confirmed a diagnosis of ALL, which depletes the body's number of infection-fighting white blood cells. Cassidie tolerated the first two rounds of chemotherapy, but her cell count plummeted after the third round of medications.

"Her belly, liver and spleen were all starting to swell," Latisha says. "It was pretty mind-blowing."

David Kalwinsky, MD, head of the St. Jude affiliate in Johnson City, Tennessee, ordered a genetic test that revealed Cassidie had inherited a defect for the enzyme thiopurine methyltransferase (TPMT). This defect prevented her from metabolizing the anti-cancer drug 6-mercaptopurine (6MP). As a result, Cassidie's tiny body was amassing dangerously high levels of the toxic drug. Although the defect had not previously been seen in infants, St. Jude studies showed that TPMT-deficient patients could still benefit from 6MP if their doses were decreased. "She started taking only a quarter of the pill each time, and everything has been fine ever since," Latisha says.

COURTESY OF LATISHA JACKSON

A genetic test developed at St. Jude helped save Cassidie Jackson, now 2, from taking in too much of an anticancer medicine that fought her leukemia but also produced harsh side effects because a genetic defect hampered her ability to metabolize the drug.

With pharmacogenomics, a patient's own genes could tell you exactly which drug is likely to work best.

The TPMT mutations were discovered at St. Jude, as was the genetic test that is now routinely used by hospitals to screen children before 6MP is administered. The St. Jude discovery offers one example of how tailored treatments work when a single genetic variation interferes with drug response. While clearly of great importance, Evans calls this the "low-hanging fruit" of pharmacogenomics and says the science's full potential won't be realized until researchers discover more of the multiple gene variations that influence drug responses.

U.S. DEPARTMENT OF ENERGY HUMAN GENOME PROGRAM, HTTP://WWW.ORNL.GOV/HGMIS

Hard work ahead

Completion of the Human Genome Project sparked dreams that medical breakthroughs would instantly materialize once scientists fashioned a map of the body's 30,000 genes. The reality is that meaningful research takes time.

"We're dealing with diseases that require at least 10 years of follow-up to see what goes on with patients in the long term," Relling says. "There's nothing you can do to speed up that process. St. Jude has the advantage with a head start of about 15 years in its pharmacogenomics research, and we're just now getting back mature data. Some people are starting at point zero."

In her roles on a Food and Drug Administration pharmacology committee and involvement in multi-institutional pharmacogenomics and treatment groups, Relling is urging fellow scientists to begin incorporating pharmacogenomic studies into their clinical research. She says the slow reaction to jump on the bandwagon is due in part to the difficulty in obtaining federal funding for what is perceived as a mundane aspect of research.

"There really isn't anything sophisticated about keeping track of each medication you give a child and knowing exactly when they do and don't get side effects, but you cannot do pharmacogenomic research without that," Relling says. "It just takes hard work, time and money, but we feel that the payoff will be great."

According to Evans, St. Jude has more extensive and detailed follow-up of children with cancer than any other hospital in the world.

BUDGETSTOCKPHOTO.COM

Leading the way

The more glamorous side of pharmacogenomics has been the emergence of DNA microarray technology, which allows researchers to screen thousands of genes at once to reveal a person's genetic fingerprint. Evans says that better diagnostic tools will be needed so that doctors will be able to translate microarray data into treatment plans.

"A doctor 20 years from now is not going to look at a DNA sequence output for an individual patient and be able to say, 'Okay, this is how I pick the drug,'" says Evans, who likens the results of a genetic test to the barcodes on a can of tomato soup. "You can't figure out what the soup costs by looking at it on the grocery store shelf; you have to take it up to the scanner to find out that it costs $1.79. So a genotype is like a bunch of barcodes, and the readout is going to tell you what that means."

Developing tools that can read the hundreds of thousands of genetic variations could take time. Moreover, before pharmacogenomics can be clinically successful, legal assurances are needed so that genetic information cannot be used by insurance companies to discriminate against patients with high genetic risk for health problems.

"We're still in the transition period with pharmacogenomics," Evans says. "These are early days, and nobody yet fully knows what impact it will have."

We're trying to bring the power of the human genome to kids with cancer and other catastrophic diseases.

Pharmaceutical companies are among those unsure of what to make of tailored therapies, seeing little financial benefit from producing limited quantities of drugs that could help small segments—like children with leukemia—compared to blockbuster drugs that can be sold to the masses. Companies could have even less incentive to keep certain drugs on the market if genetic testing further shrinks populations into subsets.

"St. Jude pushes and makes sure drugs continue to be available for pediatric diseases, even when they aren't necessarily commercial successes. There aren't many other places that have the resources to do so," Relling says.

Whatever the future is for pharmacogenomics, St. Jude will continue its quest to bring the benefits of individualized therapies to kids around the world. "We're trying to bring the power of the human genome to kids with cancer and other catastrophic diseases," Evans says. "We're interested in taking this research and developing it into therapies for childhood cancer. That's been our mission for 40 years."●

SETH DIXON

St. Jude scientists Mary Relling, PharmD, and William Evans, PharmD, opened the first pharmacogenomics research plan for St. Jude patients almost two decades ago. Now they're leading some of the world's first pharmacogenomic studies in children with acute lymphoblastic leukemia.

Beginning the day after Thanksgiving, businesses nationwide will offer ways for holiday shoppers to support the work of St. Jude.

BY JOE HANNA

Thanks & Giving

St. Jude Children's Research Hospital and an impressive group of major companies nationwide will make this holiday season not just about shopping and buying gifts, but about giving to save children's lives.

The event is called Thanks & Giving, and it is happening across the country. From the day after Thanksgiving, Friday, November 26, until the end of December, stores and businesses throughout the United States will offer ways for customers to support the work of St. Jude and help in the battle against cancer and other childhood catastrophic diseases.

St. Jude patients Camble Kirkhove and Ali Abdelaziz model infant rompers available for sale through Thanks & Giving. A variety of limited edition gifts are also offered on the promotion's Web site, www.THANKSandGIVING.com.

"Just by doing the shopping you already plan to do, you can help save a child's life this holiday season," says Marlo Thomas, National Outreach director for St. Jude.

"While you are out shopping in the malls, just look for the stores that carry the St. Jude Thanks & Giving logo. You'll not only be doing your regular holiday shopping, you'll also be giving to the kids of St. Jude," she says.

Stores such as Target, 7-Eleven, CVS/pharmacy, Toys "R" Us, The Athlete's Foot and Kay Jewelers—along with companies such as The Walt Disney Co., Ticketmaster, Time Inc., FedEx, American Express and Domino's Pizza—will give customers a host of opportunities to support St. Jude. Whether through the purchase of a gift card, teddy bears, St. Jude patient-designed merchandise, a donation at check-out or an outright contribution, shoppers will be lending help to the ongoing research of pediatric cancer and other deadly diseases.

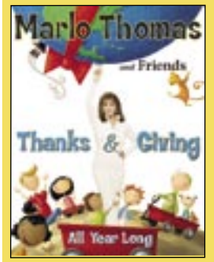
Thanks & Giving will launch on the *Today* show Tuesday, November 16. During Thanksgiving week, Thomas will appear on that show each day, culminating in a shopping trip with *Today* host Katie Couric on the Friday after Thanksgiving. Yahoo! (*yahoo.com*) will feature St. Jude on its main page that week, along with information on how to donate to the hospital.

But it's not just companies and stores that are helping St. Jude with the launch of this annual holiday event. A number of celebrities are also lending their star power.

"When my father started St. Jude, the stars of his time—Frank Sinatra, Bob Hope, Sammy Davis Jr., George Burns, Ella Fitzgerald—helped him raise the first funds that built the hospital," Thomas says. "And it's so satisfying that now the stars of our generation have become a part of the St Jude family—stars like Billy Crystal, Willie Nelson, Faith Hill, Sarah Jessica Parker, Robin Williams and many more."

The centerpiece of Thanks & Giving is a new book and CD that Thomas has compiled, which, in the spirit of her landmark *Free to Be …You and Me,* includes stories, songs and poems for "children and the grown-ups in their lives." Titled *Thanks & Giving All Year Long,* the book includes contributions from award-winning children's authors, as well as pieces by Tiger Woods, Mel Brooks, Ray Romano, Hillary Duff, Whoopi Goldberg and writers from Sesame Street.

"The book is about giving and sharing," says Thomas, "as well as making fun of their opposites—stinginess and bullying. It's about family holidays—those that work out and those that are a disaster. It's about presents—some that are great and some that are not so great. It's about the funny side, as well as the joyous side, of thanks and giving." The book will also feature artwork from such acclaimed illustrators as Maurice Sendak, Matt Groening and Arthur creator, Marc Brown.



Marlo Thomas, national outreach director for St. Jude, has published a new book that includes contributions from an array of well-known writers and public figures.

National TV spots featuring Robin Williams, Sarah Jessica Parker, Antonio Banderas, Ray Romano and Will Smith—as well as St. Jude patients Jesus Peneda, Summer Wilson and Matthew Haggerty—will be aired during the month. These stars will appear in trailers about St. Jude on more than 20,000 movie screens in theater chains throughout the country. The trailers will also be seen on American Airline flights.

Thanks & Giving is an extension of the Shower of Stars event that took place in April 2003 at St. Jude when CEOs such as Michael Eisner of Disney, Ann Moore of Time Inc., Terry Semel of Yahoo! and Barry Diller of IAC/InterActiveCorp visited St. Jude. After a day of orientation, they offered to help create a national campaign to raise both awareness and funds for the institution.

"Once they visited our campus and listened to the groundbreaking work that was presented by our scientists and clinicians, they were hooked," Thomas says.

"They caught what we call 'St. Jude fever.' And once someone gets the fever, we've got them for a lifetime."

"People around the world hear about how St. Jude has improved cure rates for childhood cancer," she says. "They hear about how science moves quicker at St. Jude than anywhere else, thanks to researchers and doctors working under one roof." Thomas also says that St. Jude Nobel laureate Peter Doherty, PhD, and the hospital's many other award-winning scientists are "magnets for the best young scientific minds in the world, many of whom wish to be mentored by our outstanding faculty."

Thomas says that working with her brother, Tony, and her sister, Terre, along with other dedicated partners involved in the project, is energizing. "The mission," says Thomas, "is finding cures and saving children," a shining goal that is at the heart of her continued commitment to the hospital her father founded.

"The bond that is my connection to St. Jude is always that the research we do saves the lives of children around the world," she says.

"That's all I ever need to stay motivated—to know that the money we raise goes to continue the research that will save children's lives so someday every parent will be able to take back to their home and family their beloved, healthy child." ●

You can buy these and other St. Jude items from the comfort of your own home by visiting www.THANKSandGIVING.com.

PHOTOS BY JERE PAROBEK

Big Ben BOWEN

A small boy, a large story rippling across the country

By Victoria Tilney McDonough

When Tom Bowen suggested that he and the other firefighters on his squad drop to their knees at the site of Ground Zero to pray for the faceless man they had just pulled out of the rubble, he didn't realize how his small act of loving kindness would come full circle.

The memories that come with being a search and rescue worker after September 11, 2001, are impossible to forget. They are difficult to manage or explain, difficult to file away in any box with a name. Life becomes a different landscape.

In early 2004, Tom and his wife, Jennifer, felt as if they were just starting to emerge from the intensity of the experience; life was beginning to return to a new version of normal. But in March, they were hit with their own tragedy when their youngest son, Ben, just 16 months old at the time, was found to have an often fatal form of brain tumor. When the tumor was discovered and the swelling in Ben's brain prompted doctors to schedule emergency surgery, the Bowens were told he would probably die. They could have 15 minutes with their baby.

Only a moment

Tom Bowen, like his wife, has always been a person of faith. Faith, he explains, is abstract until put to the test. As a firefighter, he has learned about the "tools of the trade," the equipment that must be in place before entering a burning building.

"Often the tools are cumbersome, heavy and even frustrating," he explains. "They take time to put on and use, but you rarely see firefighters running around crazy. You'll see them walk off a truck really calm, pulling on their equipment, everything a method. There's a system and a centeredness that goes with it. I think the same applies to our faith, our lives. With Ben, we've been challenged to put on the tools of the trade and go to work. Our faith is either what we believe or it's not. You have to act accordingly, believe God; not just believe in him."

Few search and rescue workers were prepared for what they had to do in the wake of 9/11. There was no precedent. Tom and his team were pulling body parts out of the rubble; each hour the hope of finding anyone alive, or whole, evaporated. Tom remembers a particular recovery in which they were able to find the man's wallet.

"It was the first time we recovered someone when you actually saw who they were; you know, you see their face in the photo and those of their family, their kids. I remember looking over at the guys and saying, 'Do you mind if we… it's a small thing…but let's stop and pray for this man and his family.'" So eight or nine firefighters knelt on the hot ground—their hard hats tight on their heads, their eyes open—and prayed.

From then on, each time they found someone, they would stop, if only for a moment, and say a prayer for that soul and his family. "It just makes you wonder how many opportunities in life we've let pass, afraid of what others might think or do—when the reality is that you need to pay attention, to do the small acts that might seem like nothing at the time but always come back around," Tom says.

One of the first e-mails in the guestbook on a Web site the Bowens set up for Ben is from the son of the first man for whom those firefighters prayed. A few weeks after Ben's cancer was diagnosed, the teenager wrote, "I will keep Benjamin in my prayers because I know I have been in yours." This boy and his family, among others, have become close friends of the Bowens.

An unplanned plan

Ben and his older brother, Eli, were both early walkers and talkers: healthy, curious boys. The Bowens knew something was not right when Ben became lethargic and then started throwing up regularly and slept almost solidly for three days. They went to their local hospital in West Virginia only to be told that nothing was wrong. The parents said they were treated as if they were hypochondriacs. A CAT scan was

LAURA HAJAR

LAURA HAJAR

"When we came to St. Jude, we just said that no matter what it takes, we would keep the family together," says Tom Bowen, with Jennifer, Eli and Ben. When asked what he would want Eli and Ben to remember about this time, Tom answers, "Two words: God and family. Believe God, and love your family."

ordered and then cancelled. They were told to go home.

Finally, the Bowens' family doctor insisted on a CAT scan. Then the faces who had told them it was nothing returned with bad news. Because of timing and a lack of hospital beds, Ben was flown to a hospital in Cincinnati. There, they learned that Ben had an atypical teratoid rhabdoid tumor (ATRT), a rare and insidious brain tumor that can grow rapidly and is almost impossible to remove fully. This tumor is difficult to treat with chemotherapy or radiation because of the location and type, and oftentimes the young age of the patient. Things did not seem to be in the family's favor.

That night, Ben underwent the first of four operations. After a touch-and-go month when Ben did not fare well physically or emotionally, the doctors referred them to St. Jude Children's Research Hospital.

"God—the world—has a plan for us though we don't usually know what it is or understand it," says Tom. "We feel very fortunate that everything unfolded as it did and we ended up at St. Jude. At the time, everything seemed terrible. But when you look back, you see the plan."

Smiling Big Ben

Almost everyone who has met Ben remarks on his smile. He's a little guy, now bald, with a large scar ratcheted across his head. And yet, there he is smiling, playing with his brother or pointing emphatically at a giraffe in a favorite picture book.

"Ben and his family definitely stand out. They've already touched so many people. It's as if God is using them to help others, to show others how to be strong," says Rebecca Yates, a nurse in the Medicine Room. "Sure, like anyone else, they have their days when they feel angry and confused, but they try to rise above that and use their energies to heighten awareness about cancer, to raise money for brain tumor research. There's just something about them. They know everyone in the halls and all the kids and their parents in the Medicine Room. And little Ben is always happy, such a trooper. He was getting treatment through a port in his head one day and instead of crying he just sat there, smiling, watching a *Bear and the Big Blue House* video."

People often ask Jennifer how she and Tom manage not to be sad every day. She responds that they're fighting it and going on with life. "The biggest way to keep from being sad is being with Ben," she says. "He wakes up smiling. We focus on today and then tomorrow. I used to be a big planner; now I just think about today: maybe tomorrow we'll go to the zoo. There is definitely a shift in perspective. It's freeing, actually."

Bigger than Ben

When Eli says his prayers at night, he says: "Please let baby Ben's head feel better, and help the doctors and nurses." At only 3, Eli, like his parents, knows that what's going on in his family's life is bigger than Ben. In late summer of 2004, Ben's Web site had received more than 114,000 hits. The guestbook is filled with more than 3,600 messages from friends, family and strangers from across the country: people who know or have met Ben; people who have never met him; people who have only heard about him through a friend, or even from a waitress.

"I am struck with the family's faith, their optimism, their sense of humor," says Maryam Fouladi, MD, of St. Jude Hematology-Oncology. "You walk down the hall with them and they already know everyone. They are helping other families; supporting other kids on their Web site, through their actions, in their prayers," she says. "Raising awareness, money and hope for this cancer is almost like a crusade for them. It's what seems to give them strength."

Fouladi knows that the Bowens' road is a difficult one. ATRT was only distinguished from other brain tumors less than 10 years ago, and the prognosis is extremely poor.

ATRT treatment at St. Jude includes intrathecal therapy, in which chemotherapy is administered into the head and spine for quick and direct absorption; and 3-D conformal radiation therapy, in which radiation beams are focused from several directions at the tumor site, helping to save brain function.

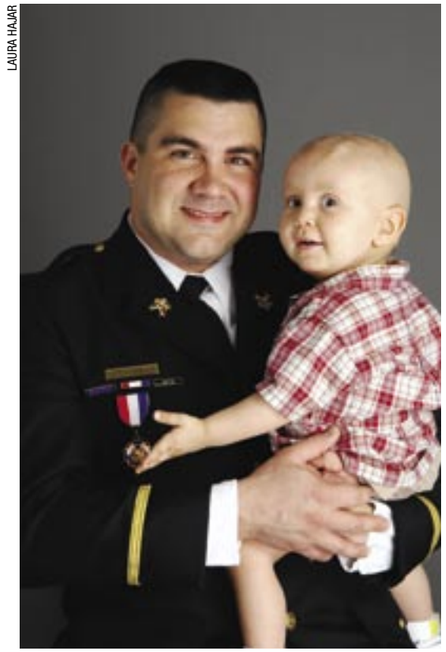
As of mid-August, Ben had completed more chemotherapy and undergone his fourth operation. But the tumor had not responded to the treatment. He was facing six additional weeks of radiation therapy.

"The Bowens are taking life head on, taking what God gives them and counting their blessings," Fouladi says. "They are lovely people. Their keen sense of family no doubt makes a difference for Ben."

Coming full circle

A woman who lost her husband in the 1995 Oklahoma bombing received a quilt from someone as a gesture of kindness. After 9/11, this woman sent it to one of the World Trade Center widows, who in turn sent it to the Bowens when Ben got sick. The Bowens say they will know to whom they should pass the quilt when the time comes.

"It's amazing how things come full circle, how life's little lessons—listening to people's stories, understanding that God has a purpose and a plan for everything—come back to us in many forms and colors," says Tom.



LAURA HAJAR

ELIZABETH WALKER

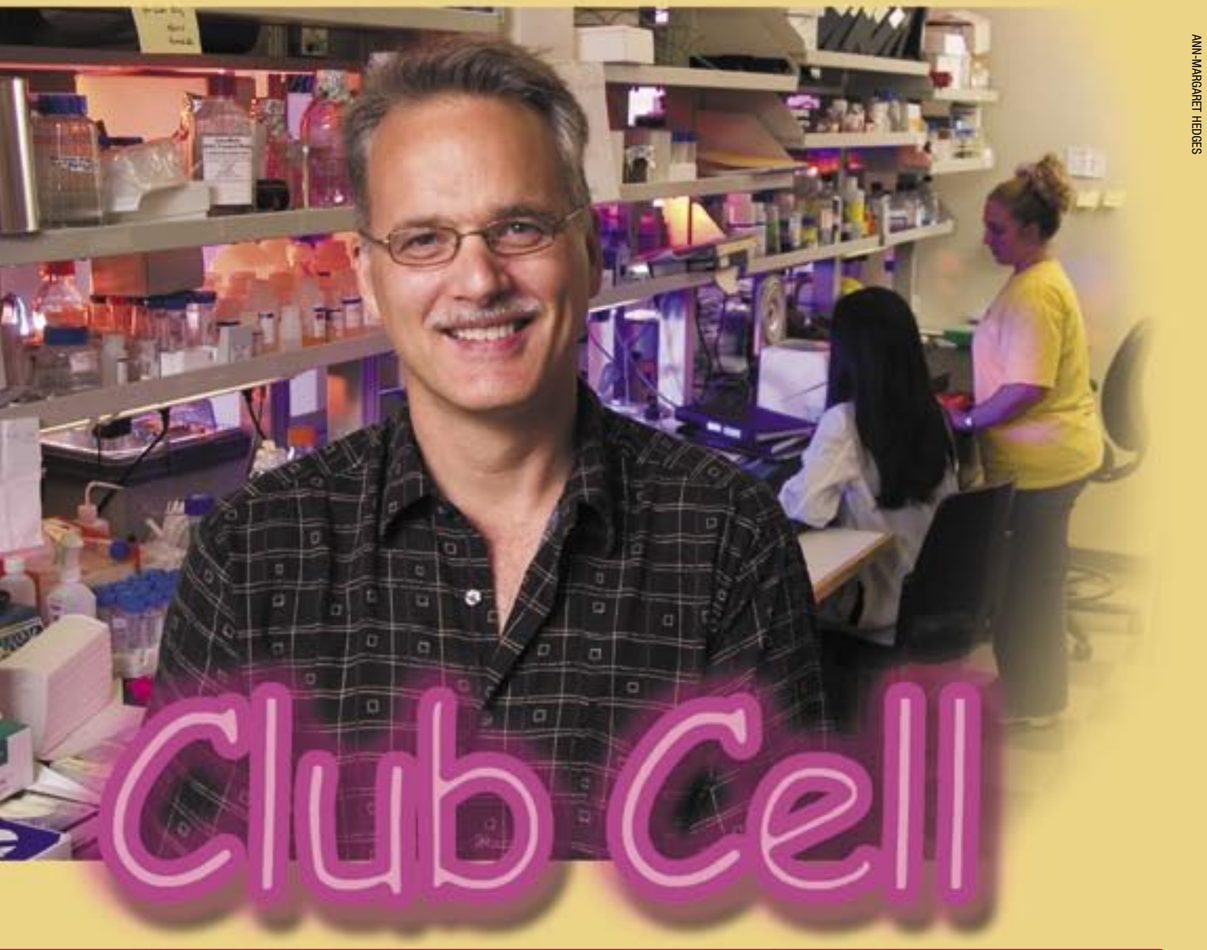
Firefighter Tom Bowen led his fellow rescue workers in praying for victims and their families as each body was pulled from the rubble after the September 11, 2001, attacks on the World Trade Center. When Ben later became sick, the victims' families returned the favor by rallying around the Bowens.

When Jennifer thinks about all the people who have entered their lives since Ben got sick, she says, "I think God is performing miracles on Ben all the time, regardless of how it ends. It's amazing how many people have been touched by hearing his story and who have connected with us and others through ours and their own stories."

In many states across the country, people are talking about Ben, his cancer, the strength of the human spirit and how even one small gesture can change a life. "Everything happens for a reason," says Carol Cangialosi, who lost her nephew Stephen Cangialosi in one of the World Trade Center towers, and whose family stays in contact with the Bowens. "Tom came into our lives when we needed to try to understand something that cannot be understood. When we heard about Ben, we just rallied around Tom and tried to support him as he did us. That Tom came into our lives is a good thing. He helped my husband, Jerry, and me gain a sense of closure."

For Karen Cangialosi, Stephen's widow, Tom was the one who was able to answer some of her questions. "I know everyone tried so hard and that meant so much. I told Tom: 'I know you tried to bring him home to my boys and me.'"

When Tom and Jennifer watch their two boys playing on the jungle gym, jumping and laughing and sharing their sibling secrets, they know that they're not alone. Around them everywhere are friends and strangers alike all living out their own stories, stories that overlap, circle upon circle as a stone skips across the skin of a smooth lake.●



ANN-MARGARET HEDGES

Club Cell

BOUNCERS, OR PROTECTIVE PROTEINS, HAVE THE TASK OF ESCORTING MOLECULES OUT OF CLUB CELL. ST. JUDE RESEARCHERS INVESTIGATE HOW TO USE THESE PROTEINS TO FIGHT CANCER.

Club Cell is the new hang-out spot. It has a large staff of burly bouncers who can escort certain guests out of the club. Each bouncer has a unique job to escort some guests out of certain exits he guards. But in spite of this security system, not everything inside the club runs smoothly.

It's time to call in researchers at St. Jude Children's Research Hospital. Both normal and tumor cells have proteins in their membranes that act like bouncers to escort some guests out of the cells. When these protective proteins are functioning, chemotherapy drugs cannot accumulate and kill the offending cells. Top-notch investigators at St. Jude are seeking ways to block the function of certain bouncers so they can send in chemotherapy drugs and save the day. But if the bouncers in normal cells are blocked and chemotherapy drugs accumulate in those cells, the results can be catastrophic.

John Schuetz, PhD, of St. Jude Pharmaceutical Sciences heads a team charged with investigating the function of the protective proteins that guard each exit. Schuetz says that sometimes chemotherapy does not work because cancer cells have many bouncers who escort chemotherapy drugs out of the club. He and his team are still trying to find out more about these proteins. "In the lab, we are trying to understand the function of each protein," Schuetz says. "We know what about one-quarter of them do, and we are working on researching more."

About a decade ago, researchers thought there was only one of these proteins, which transported molecules out of the cell. "Now we know there are many," Schuetz says. "There are about 50 of these proteins. Our lab is intensively studying a couple of those. What we've done with the two recent ones is to identify their unique biological roles."

By identifying more protective proteins, researchers can ultimately combine chemotherapy drugs with inhibitors that block certain protein functions. "We envision co-administering the chemotherapy drugs to patients with an inhibitor to block the protein at the time when the drug peaks at high levels. The drug can then more effectively kill the tumor cells," Schuetz says.

BY CARRIE L. STREHLAU

Blocked exit doors

Drugs do not enter the club through specific doors; they can just move in through the cell membrane. But they can only exit the cell with the help of a protective protein. Schuetz and his colleagues have learned to take exquisite care when blocking the exits from *Club Cell*. For instance, the researchers recently discovered that inactivating a protective protein in leukemia cells to make the cells more vulnerable to chemotherapy might also make healthy, blood-forming cells more sensitive to the toxic effects of those same drugs.

The St. Jude researchers based their conclusion on results of a study of a molecule whose normal function is to rid hematopoietic stem cells (HSCs) of a potentially toxic molecule called heme. HSCs are parent cells in bone marrow that give rise to red and white blood cells. Heme is an oxygen-carrying molecule that is a key part of enzymes used by cells to extract energy from food and by red blood cells to carry oxygen to tissues.

When oxygen levels are low—a situation known as hypoxia—the cell wants to make as much heme as possible to trap as much oxygen as it can. But the cells must also protect themselves from excess heme, which can poison the cell. The cell makes what is known as the breast cancer resistance protein (BCRP), which is capable of binding to heme molecules and transporting them out of the cell.

Our work has significance for those who are attempting to block the protein in order to enhance chemotherapy.

According to Schuetz, the ability of cells to rid themselves of excess heme is especially important in the bone marrow, where HSCs are normally exposed to a low-oxygen environment that stimulates the cells to produce more of this molecule.

Kicking toxins out of the club

Brian Sorrentino, MD, St. Jude Experimental Hematology director, has expertise in blood and bone marrow cells and developed a laboratory model that lacked the protective protein BCRP. Researchers in the Schuetz lab then used this model to test the role of BCRP in cell survival under low oxygen conditions. In addition to heme, BCRP carries a variety of toxic chemicals out of cells, including certain drugs used to treat leukemia. Researchers outside of St. Jude are developing molecules that block BCRP in leukemic cells and make them more vulnerable to chemotherapy. However, drugs that block BCRP in leukemic cells would also block this molecule in healthy HSCs, leaving them vulnerable to toxic chemotherapy drugs and less able to survive in low oxygen conditions.

"If BCRP function is blocked for a long time, the patient's normal blood-forming cells could be depleted," Schuetz says. "And that would reduce the body's ability to produce healthy red and white blood cells, which would certainly complicate the patient's medical condition."

According to Sorrentino, the main message this research sends to investigators is that the blocked protein may protect stem cells from oxygen starvation. "We don't think that blocking the protein is a good idea, since it could render stem cells vulnerable to other harmful elements," Sorrentino says. "Our work has significance for those who are attempting to block the protein in order to enhance chemotherapy. These strategies could be harmful to stem cells not only as they relate to hypoxia injury, but also by increasing the sensitivity of normal bone marrow stem cells to chemotherapy drugs."

The double whammy

Schuetz and his team developed a laboratory model that lacked a transporter found in the brain's protective barrier. Researchers in his lab then collaborated with Clinton Stewart, PharmD, also of Pharmaceutical Sciences, who has been studying drug delivery to the brain. The collaborators discovered that a protective protein called Mrp4 prevented some chemotherapeutic drugs from entering the brain. This protein was also known to protect tumor cells from chemotherapy drugs.

"The benefit of this research is a double whammy for brain tumors," Schuetz says. "If you can block this protective transporter you can get more drug into the brain and also more drug into the tumor so you stand a better chance of killing the tumor."

Schuetz is also collaborating with St. Jude colleagues such as Erin Schuetz, PhD (Pharmaceutical Sciences), on genetic variations in the transporters.

"Someone may have a particular protective protein that does not work as well as that same protein would in another person," he says. "Knowing this, we might be able to explain why a drug works in one person and not in another. Within five years, I hope to see pre-clinical models for all of the protective transport proteins. This will help us really predict what a transporter will do and more accurately adjust treatment to fit a patient's needs. That will have tremendous effect on our patients at St. Jude."●

brainPOWER

St. Jude provides leadership for national brain tumor consortium.

By Victoria Tilney McDonough

James Boyett, PhD

ANN-MARGARET HEDGES

Anyone who has ever helped a kid with a science project knows the importance of conducting a well-designed and carefully executed study. Pretty pictures and clever display boards will not yield that coveted A+; the youngster must first keep scrupulous records and engage in some elementary statistical analysis.

Scientists seeking cures for tumors of the central nervous system know the importance of creating innovative studies backed by high-quality statistical science. Under the leadership of St. Jude Children's Research Hospital, a prestigious group of hospitals and research institutions are working together to do just that.

St. Jude is the operations and scientific center of the Pediatric Brain Tumor Consortium (PBTC), which was formed by the National Cancer Institute in 1999. Most children with primary brain tumors in the United States go to St. Jude or one of the other nine PBTC institutions for diagnosis and treatment. These institutions pool their intellectual resources and statistical data to identify superior treatments for children with brain cancers and to further understand the biology of central nervous system tumors. Larry Kun, MD, chair of St. Jude Radiological Sciences, leads the PBTC steering and scientific committees.

Before the PBTC was conceived, James Boyett, PhD, chair of St. Jude Biostatistics, saw the need for a central location from which to manage millions of pieces of data. To coordinate the activities of institutions spread across the nation, he developed an Operations and Biostatistics Center for the PBTC. Boyett first became interested in multi-center trials back when computers were the "size of refrigerators and as slow as Christmas." Today he serves as principal investigator of the PBTC and executive director of its high-tech nerve center, the Operations and Biostatistics Center.

Boyett and his team have created a secure electronic means of moving neuro-imaging files. "These are huge, encrypted files," he says. "We collect them from the PBTC institutions and send them to the physical neuro-imaging center established at Harvard, where they are evaluated. This technology has allowed us not only to collect pictures but also to collect the data behind them and to do it all electronically."

Operations and Biostatistics Center staff members also masterminded a novel data transfer system that ensures smooth collaboration. "We've established a nearly paperless multi-center data management system where all the PBTC hospitals have laptops with software we've created and set up to securely collect the protocol data for analysis and reporting," Boyett says.

All of these technological advances help scientists take the methods they learned in elementary school to a higher level. "A protocol arises from a question," Boyett explains. "It's up to us to figure out how best to answer that question. First and foremost, the study has to have a good statistical design so that patients who consent to participate in the research truly contribute to a better understanding of these diseases. From there, it must be conducted to a T so as to get as close as possible to answering that question."

Thanks to St. Jude leadership and collaborations, scientists studying brain tumors are moving ever closer to cures. And that rates an A+ for sure.●

JOHN ZACHER

St. Jude patient Ryan Zimmerman sits on the lap of Ronney Snell, who made prosthetic devices for children at the hospital and helped establish the institution's Rehabilitation Services department. "Mr. Ronney was Ryan's hero," says Ryan's mom, Marilyn. Snell's friends and family have created a $50,000 endowment in his memory.

Putting Children First

By Alicia H. Matthews

He restored a sense of normalcy to countless St. Jude patients. Now Ronney Snell's legacy continues with an endowment to Rehabilitation Services.

In the early 1960s, at a time when survival rates for childhood cancer were slim and the most common treatment for solid tumors was amputation, the late Ronney Snell made prosthetic devices for the children of St. Jude Children's Research Hospital. As the third generation in his family to enter the field, Snell believed in caring for the child as a whole and did his best to restore a sense of normalcy to young patients.

"Ronney specialized in helping children," says his wife, Karrene. "His philosophy was to heal the child of the illness and help the whole child in the process. He wanted them to feel normal even though they may have lost a limb."

Snell's relationship with St. Jude began when he started providing prosthetic devices for children with osteosarcoma, the most common form of bone cancer in children and adolescents. Snell not only developed the parts, but he also taught the patients how to get the most efficient use from the devices. His dedication to the children grew deeper through the years.

"St. Jude was his love, and his compassion and love for the children motivated him to do his job every day," says Karrene. "As his family, we understood that love and grew to love the hospital as well."

Snell made it clear that he always thought of the child first when designing a prosthetic device.

"When Ronney was with a patient, that child knew that 'Mr. Ronney' was focused on him," says Lola Cremer, director of Rehabilitation Services. "No matter how severe the disability, the image reflected back to the child was one of wholeness. I never saw Ronney fit a brace or a prosthesis without considering carefully what that device would allow the child to do that he couldn't already do."

Snell's legacy pervades the hospital's Rehabilitation Services department, which he helped establish. In honor of his commitment to St. Jude patients, Snell's friends and family dedicated a $50,000 endowment in his name to the hospital—the Ronney Snell Memorial Fund.

"Ronney loved to fly, and he loved to sail," recalls Cremer. "He was continually looking up and declaring it a good day for one or the other. He taught me to look up to see the big picture—to focus on the difference that could be made in the life of a child…for that is all that really matters. He taught us all to 'adjust the sails' to take children where they needed to go." ●

To learn about ways to give, call ALSAC Gift Planning at (901) 578-2081 or toll free at (800) 830-8119 ext. 2081.

SETH DIXON

Country Living

Nathan Wright finds inspiration from God, his grandparents and the great outdoors.

By Tanuja Coletta

By the time the sun begins its heavenly ascent over southern Illinois, Nathan Wright's coffee thermos is already half-empty. Awake since 4:45 a.m., Nathan and other duck hunting guides unload their gear from pickup trucks and trek down to the frosty marsh where hundreds of preset decoys greet them. The young men shuffle around in silence, inhaling the crisp, earthy scent of their surroundings.

As he does every morning from October to January, Nathan gingerly leans back into his camouflaged duck blind and turns his eyes upward, patiently awaiting nature's grand show. On most days, he blows into his duck call as if it were a harmonica, coaxing flocks of green-headed mallards to glide forth through the blue-grey sky. Even when the ducks are no-shows, the experience brings Nathan comfort.

"Sometimes, I find myself just looking up into the clear sky and letting the wind catch my face," he says. "There's a sort of peace in that."

Nathan has always found refuge in the countryside, whether tromping through woods or fishing on a quiet stream with his grandfather. Nathan is certain that when a rare blood disease threatened to end his life many times over the course of 15 years, it was the same swift winds that rush over neighboring corn fields and course through his body that gave him the power to fight back.

Now 22, Nathan lives each day as if it were a gift. "I'm making up for lost time," he says.

Heading south

The first sign that something was wrong with Nathan came when he was a preschooler living with his grandparents, Austin and Mary Wright.

"He would lay his little hands on our kitchen table and would get bruises," Mary recalls. "And he was taking a lot more naps than normal 4-year-olds. We would often have to carry Nathan because he was too weak to walk that much. That was our clue that there was something seriously wrong with this child. It scared me half to death."

A trip to the local hospital was followed by six weeks of tests at a St. Louis medical center. When doctors couldn't come up with a diagnosis, they told the Wrights to "take Nathan home and see what happens," Mary says. "I thought, 'No, I don't think so.'" Instead, they took Nathan to their family doctor. He took one look at Nathan and said, "This kid is going to St. Jude."

Three days later, physicians at St. Jude Children's Research Hospital told the Wrights that Nathan had aplastic anemia. The disorder results from the unexplained failure of bone

SETH DIXON

Mary Wright is thrilled to see her grandson Nathan live out his dreams after beating aplastic anemia. "I can't say enough good things about St. Jude and the way they treated him," she says. "We feel totally blessed."

marrow—the spongy tissue within bones—to produce red cells, white cells and platelets, the blood components that transport oxygen, fight infections and prevent bleeding. Nathan began a journey that only a handful of people per million embark upon each year. Up to a third don't survive.

"There were several children who Nathan became friends with who died from the disease," Mary says. "We prayed to God to see Nathan through."

St. Jude to the rescue

Mary's prayers were answered when they met Winfred Wang, MD, the physician who would guide Nathan's therapy for almost a decade. "We love him," Mary says. "Dr. Wang never gave up on Nathan. He always worked so hard to save him."

It wasn't easy. Wang, a member of St. Jude Hematology-Oncology, says Nathan's condition was complicated. "There are different types of aplastic anemia, and most of the time, there is no specific cause you can identify," Wang says. "That was the case with Nathan."

A bone marrow transplant is the preferred therapy for aplastic anemia patients. However, because Nathan did not have a matched bone marrow donor, he was immediately started on blood and platelet transfusions, as well as a regimen of drugs to suppress his immune system. From 1984 to 1991, Nathan and his grandparents drove down Interstate 55 to Memphis every two or three days with hopes that the transfusions would jolt Nathan's bone marrow into producing a healthy number of blood cells.

"Sometimes I could go four or five days without a transfusion, but that was rare," Nathan says. "It all depended on if my platelet count would spike up high enough."

Eventually, Nathan had so many transfusions—more than 400—that his body got selective about which ones it would respond to. Whereas a healthy platelet count is between 150,000 and 400,000, Nathan's would sometimes drop to 1,000. "That was panic time, because those transfusions were keeping him alive and now our number of donors was getting scarce," Mary says.

Nathan's caregivers noticed that his counts rose higher than normal when he received platelets from John McCormick, PharmD, of St. Jude Pharmaceutical Sciences. Despite the fact that donors were supposed to be anonymous to patients, the hospital was so small at the time that Nathan's family quickly realized that McCormick's weekly donations were keeping Nathan alive.

"There were times after Nathan got a good spike that his grandfather would whisper in my ear, 'You did good yesterday,'" McCormick says.

Wang, who has never known another patient to receive so many transfusions for so many years, says Nathan would not be alive without them. After seven years, Nathan's body finally sprang into action. A couple of weeks, sometimes even a month, would pass before he needed a transfusion.

However, things would get a lot worse before they got better.

A higher calling

Most little boys live for the thrill of lunging for home plate or racing bikes at warp speed, only to wear the resulting scrapes and scabs as badges of honor. Nathan couldn't count on his body to heal even after the slightest scratch; in fact, he studied with a home tutor to avoid the risk of injury at school. Yet, that never stopped him from testing the limits of his body or the patience of those who loved him.

SETH DIXON

Nathan Wright lays out decoys during a morning of duck hunting. After beating aplastic anemia, he says he's making up for lost time.

"He just wanted to be a normal boy," Mary says. "Once, he talked Dr. Wang into letting him play baseball, and I thought, 'Lord, have mercy!'" Wang only granted permission after Nathan promised to play in the outfield and wear a special vest to protect the central line in his chest.

"Well, wouldn't you know it, in his second game, someone hit a long one and got Nathan right in the mouth," Mary says. That night was one of several when the Wrights made an emergency trip to St. Jude to staunch the bleeding. Once at the hospital, Nathan charmed the staff out of scolding him too badly.

"He was such a cute little guy, and the whole family was so friendly," says Margaret Edwards, RN, one of several Pharmacy research nurses who have become longtime friends with the Wrights. "We fell in love with Nathan. He always had such a great attitude."

Nathan attributes his positive outlook to his upbringing. "I was lucky because I had my Grandpa with me," he says, "All we did before my tutor came and after my tutor left was fish, hunt and run through the country. I don't know if that filled me up with a good spirit or good heart or a good will to live, but I got a lot from the country, and I love it out here."

Truly a miracle

After Nathan's bone marrow function improved, things looked up for Nathan—but not for long. In 1995, when Nathan was 13 years old, his grandfather succumbed to a yearlong illness. "It wasn't long after he passed away that things went downhill again," Nathan says. A routine blood test revealed that Nathan had developed acute myeloid leukemia (AML), a disease of the white blood cells, as well as paroxysmal nocturnal hemoglobinuria, which breaks down red cells. When a course of experimental drugs failed, a bone marrow transplant became Nathan's only hope for survival.

"Those were some tough times, but God was watching over us," Mary says. "We had our church family sending prayers up for Nathan all the time."

Two months later, a match was identified from the national bone marrow donor registry. Though the transplant was no walk in the park—Nathan spent the following 100 days receiving fluids through his veins—it did the trick. Nathan was cured of the AML, and his bone marrow started pumping out high enough levels of blood cells that transfusions were no longer necessary.

"We were all so happy, we cried," remembers Sheri Ring, RN, a research nurse. "Back then kids with aplastic anemia didn't live. Nathan is truly a miracle."

Spirit soaring

Nathan's yearly visits to St. Jude seem more like family reunions than routine checkups. Staff members quiz him about his job and love life. Last year, he even had the St. Jude logo tattooed across his back. "I guess St. Jude was like a second home for me," he says. "They watched me grow up."

Though still an avid outdoorsman, Nathan also revels in doing tasks others might find mundane like going to work at the Penn Aluminum plant and paying the note on his truck. "When I was 16, I was dying to be like my buddies and get a job baling hay in the summers, but my Grandma wouldn't let me because I was too weak," Nathan says.

Now Mary feels sincere satisfaction seeing the front door swing behind Nathan. "I feel good that he finally got there," she says, "that he can come and go as he pleases and do what he wants. He really is making up for lost time." ●

Perspective

Another Piece of the Quilt

By Amy Grant

As we all join together in promoting the hospital's mission, our actions can create a glorious patchwork of hope and healing for the children of the world.

SETH DIXON

Quilt of Dreams spokesperson Amy Grant shares a hug with 8-year-old St. Jude patient Macy Morgan.

For my daughter Millie's 13th birthday, a friend and I made a quilt that had photographs of my daughter all over it. Millie's so proud of that quilt, and it's on her bed today. My impressions of St. Jude Children's Research Hospital also resemble a patchwork quilt—a colorful jumble of memories, experiences and events that have touched my life. The first piece was cut many years ago, when I toured St. Jude, sang some songs in the lobby and met a few of the courageous families. That was such an emotional trip. But I loved St. Jude, and I saw what a great contribution music was in that environment.

A second piece of my personal quilt was fashioned during a quiet moment with a patient. On one visit to St. Jude, I met a girl who was there for the second time because her cancer had returned. The most memorable moment I've had with a patient was with that young woman. I asked everybody to leave the hospital room. She and I just sat there and sang a couple of songs. She was at such a desolate place physically. I really felt that by singing those songs and being there and sharing the music and watching her sing along… for just a minute we kind of shared the same space. She did not survive her cancer, but I still think of her today.

After I became a parent, my impressions of St. Jude assumed a deeper hue and texture. I walk down those halls, and I'm always thinking, 'Oh, that boy is just one year younger than my son." Or, "That child is just a month older than my daughter." You're constantly putting yourself in the shoes of the people there.

Another patch in my "quilt" occurred when my relationship with Target Stores enabled me to help raise money for the construction of Target Houses I and II. Families can live in these beautiful facilities while their children undergo treatment at St. Jude. I've spent a lot of time in hotel rooms, and I know what it's like to be away from home. Imagine the stress of being a parent with a sick child and living in a strange place. But then you go in Target House and think, "Oh good! A place I can close the door! Alone time! A place to throw a fit! Hallelujah!"

Lately, I've been the spokesperson for a fund-raising project that involves actual quilts—Hancock Fabrics' Quilt of Dreams project. This ambitious undertaking combines the talent and dedication of thousands of quilters around the country. Hancock designed 37 special fabrics from which individuals have been making lap quilts inspired by the hopes and dreams of St. Jude patients. It's such an affirming thing for something as useful and beautiful as a quilt to include the words of children and their wishes and dreams. I'm so excited to be a part of this project.

There are many small ways that you and I can help the patients of St. Jude. As we all join together in promoting the hospital's mission, our actions can create a glorious patchwork of hope and healing for the children of the world.

Five-time Grammy award winner Amy Grant and her husband, Vince Gill, are ardent supporters of St. Jude Children's Research Hospital.●

SETH DIXON

I can dig it

Nine-year-old patient LaTrell Peters gets into the spirit at the August 13 groundbreaking ceremony for the hospital's Integrated Patient Care and Research Building. (See related article, page 2.)