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

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New test aids tailored therapy quest

St. Jude investigators have developed a new diagnostic approach that uses antibodies to assign the brain tumor medulloblastoma to different molecular subgroups based on differences in gene expression. The new test uses commercially available antibodies and works on the fixed tissue samples pathologists use in routine diagnostic practice, which should help community physicians.

“The identification of molecular subgroups is not only important for understanding the origins of medulloblastoma, but has the potential for immediate clinical relevance,” said David Ellison, MD, PhD, Pathology chair. Ellison is first author of the study, which was published recently in the journal *Acta Neuropathologica*.

The study combined clinical, pathological and molecular factors to stratify patients as having low-, intermediate- or high-risk forms of disease, allowing a more tailored approach to therapy. Once considered a single disease, medulloblastoma is now thought to include four to six subgroups that stem from different genetic missteps. These subgroups likely respond best to different therapies and are associated with differences in outcome.

More than 500 medulloblastomas have now been subtyped using the new approach. The results come not long after an international effort led by Richard Gilbertson, MD, PhD, of Developmental Neurobiology and Oncology, showed WNT and SHH subgroup medulloblastomas arise from distinct cell types in the brain. The report also comes amid ongoing clinical trials with an experimental drug that targets the SHH pathway in adult and childhood cancers. Amar Gajjar, MD, Oncology, is principal investigator of those Pediatric Brain Tumor Consortium and other St. Jude medulloblastoma trials.

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Honored for international achievements

The International Network for Cancer Treatment and Research recently presented Raul Ribeiro, MD, International Outreach Program director, with the Paul P. Carbone Award in International Oncology. The honor recognizes outstanding contributions to oncology or cancer research in one or more developing countries by an individual from a resource-rich country.

Since taking the helm of the International Outreach Program in 1997, Ribeiro has helped establish partnerships with 19 medical institutions in 14 countries. He is also the Leukemia/Lymphoma Division director, the St. Jude Cancer Center’s Outreach Program associate director and a member of the Oncology department.

“Dr. Ribeiro has dedicated his life to the fight against childhood cancer,” said Joseph Laver, MD, clinical director and executive vice president. “He is tireless in his mission, and his efforts have improved survival rates of children with cancer around the globe.”
The scrapbooking supplies were still being unpacked on a recent rainy Wednesday evening when the first parents arrived in the Ronald McDonald House dining room and got to work documenting their St. Jude story.

Before the scrapbooking session ended two hours later, caregivers from four families had gathered around the table. Recently published St. Jude research suggests that such therapeutic scrapbooking groups increase the ability of caregivers, especially mothers, to cope with their child’s illness.

Nearly a decade after St. Jude began offering therapeutic scrapbooking as an alternative to traditional support groups, a study has found these sessions promote hopefulness, in part by helping families recognize their strengths and by expanding their support network.

“Even though the craft of scrapbooking is widespread, its use as a tool for mental health professionals is just developing,” said Social Worker Paula McCarthy (at right), lead author of the study, published in the *Journal of Psychosocial Oncology*. “I hope documenting our experience at St. Jude encourages others to try it in diverse settings with a variety of groups, young and old.”

McCarthy facilitates monthly scrapbooking sessions at Target House and the Ronald McDonald House. Caregivers use the scrapbooks to tell their stories and highlight both the patient’s and family’s strengths. The sessions also give McCarthy a chance to provide immediate support to parents and build connections that sometimes make it easier for caregivers to seek support later.

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**Great news for hemophilia program**

The St. Jude Bleeding Disorders and Hemostasis Program was recently designated as a Federal Hemophilia Treatment Center by the Maternal and Child Health Bureau. This prestigious award provides national recognition to the program and includes financial incentives that will save St. Jude approximately $1 million annually.

“The benefit of this designation is that our patients are now represented within the larger group of national patients, which means continual, high-quality standardized care,” said the program’s director, Ulrike Reiss, MD, Hematology. “The other benefit of being a hemophilia treatment center is the ability to start a drug distribution program that results in significant financial savings for St. Jude.”

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**FLIP finding offers exciting potential**

Work led by St. Jude scientists identified how cells flip a switch between cell survival and cell death in a process that involves a protein named FLIP.

The findings solve a riddle that has puzzled scientists for more than a decade regarding the dual nature of caspase-8, an enzyme linked to the cell’s suicide pathway but also essential for cell survival during embryonic development and in the immune response. Researchers identified FLIP and the silencing of another enzyme, named RIPK3, as playing pivotal roles. The study was published in the journal *Nature*.

The paper’s senior author, Douglas Green, PhD, Immunology chair, said work has begun to translate the results into potential new targets for cancer treatment and to improve understanding of the missteps that give rise to certain tumors. The work also suggests a mechanism some virus-infected cells use to subvert the immune response. “It is a rare thing to ‘cure’ a lethal mutation by removing another gene,” Green said.

“When that happens, the biology shouts out to us that this is important.”

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Mutations in three pathways important for suppressing tumors cooperate to launch glioblastoma, an aggressive brain tumor that strikes children and adults. But new research from St. Jude investigators shows those changes alone are not sufficient to cause cancer. Tumor formation requires additional mutations, some affecting different points in the same disrupted regulatory pathways.

The laboratory findings, as well as the technique investigators used to generate them, are now being used as a possible tool for understanding patients’ responses to investigational therapies that target some of the same pathways. The research appeared in the scientific journal *Cancer Cell*.

The work builds on previous studies that linked glioblastoma to disruptions in the RB1, p53 and Pten pathways, each of which has a key role in preventing tumor formation. For this study, St. Jude investigators developed a novel system that allowed them to delete the genes for which the pathways are named. Researchers then tracked the impact of those deletions.

“This experimental system provides an opportunity to initiate a tumor with specific mutations and then ask, ‘What else gives the tumor a selective advantage?’” explained the paper’s senior author Suzanne Baker, PhD, Developmental Neurobiology.

Researchers devise alternate therapy

St. Jude investigators have found an alternate chemotherapy that can be used by institutions that are unable to offer high-dose methotrexate to children with the bone cancer osteosarcoma. The alternative chemotherapy offers comparable long-term survival to the traditional therapy. The expertise and technology required for high-dose methotrexate treatment are not universally available.

The study, led by former faculty member Najat Daw, MD, also highlights a role for international collaboration in advancing clinical research. More than half of the 72 patients in this study were enrolled and treated at the St. Jude partner site in Chile. The findings appeared in the journal *Cancer*.

The paper’s senior author, Victor Santana, MD, Oncology, noted that the study focused on an alternative mix of chemotherapy agents—carboplatin, ifosfamide and doxorubicin.

“The results suggest the three-drug therapy may be a good alternative for institutions or countries that do not have the infrastructure to support administration of high-dose methotrexate,” Santana said.

Enrollment is currently underway for a multicenter trial that uses a new, more targeted drug called bevacizumab. The new study is led by Fariba Navid, MD, Oncology.
Gene linked to leukemia relapse

Despite dramatically improved survival rates for childhood acute lymphoblastic leukemia (ALL), relapse remains a leading cause of death from the disease. Work led by St. Jude investigators identified mutations in a gene named CREBBP that may help the cancer resist steroid treatment and fuel ALL’s return.

In this study, researchers found that 18.3 percent of relapsed ALL patients carried alterations in the DNA sequence of CREBBP. In contrast, the gene’s sequence was changed in just one of the patients whose cancer did not return.

Investigators believe the gene is a potential indicator of relapse risk because of the high frequency of CREBBP mutations in relapsed patients and evidence that the changes persisted from diagnosis or emerged at relapse from subpopulations of leukemia cells present earlier. Researchers also found evidence the changes occur in important regulatory regions of the gene and affect cell function, including how cancer cells respond to the steroids used in treatment. The work appeared in the scientific journal Nature.

“This study gives us further evidence that detailed genomic studies can identify important mutations that influence tumor response to treatment,” said Charles Mullighan, MD, PhD, Pathology. Mullighan and Jinghui Zhang, PhD, Computational Biology, are the study’s co-first authors.

Paul Brindle, PhD, Biochemistry, helped the team understand how the mutations affect cell function. “This study is an example of how basic research informs efforts to improve clinical care,” he said.

New MRI installed

Workers install a fourth MRI scanner in the Chili’s Care Center, enhancing its state-of-the-art imaging suite and offering the most advanced high-field MRI technology available.

“Imaging scientists and clinical investigators will use the new instrument to study children with pediatric cancers, sickle cell disease and HIV/AIDS, and also adult survivors of these diseases,” explained Robert Ogg, PhD, Translational Imaging Research division chief.

Imaging performance of an MRI is determined by the scanner’s magnetic field strength, which is measured in Teslas. The Chili’s Care Center previously housed one 3 Tesla and two 1.5 Tesla scanners. The new 3 Tesla MRI was funded by a grant from the National Institutes of Health, and will advance basic and clinical imaging research at St. Jude.

“St. Jude will be one of the few first sites in the United States to have the opportunity to work on this platform,” said Zoltan Patay, MD, PhD, Neuroimaging section chief. “This will keep us and our research on the cutting edge of MRI technology and allow us to grow as new advancements are made available.”
Zain Brown is enrolled in the RT-SARC protocol for rhabdomyosarcoma. Radiation oncologist Matthew Krasin, MD, says this study aims to achieve significant local disease control through focused radiation therapy, while minimizing the long-term effects of treatment.
Burdened

Self-sufficient and resilient, **ZAIN BROWN** is full of imagination and incredibly wise beyond his tender 4 years. As an only child, he has learned to make the most of precious playtime and navigate the intricacies of an unfamiliar world.

**By Joyce M. Webb**

There’s never a dull moment in Zain Brown’s life. His interests are numerous and varied, including arts and crafts, professional wrestling, bike riding, school, toy cars and watching *SpongeBob SquarePants*—all welcomed diversions from the challenges he has encountered since 2009.

One September morning while getting dressed for school, Zain complained of having difficulty urinating. When the problem persisted, his mother, Alisia, took him to a local children’s hospital in Jamaica.

“They did urine tests, and everything came back negative,” she recalls. A pediatrician finally referred them to a urologist, who ordered an ultrasound. That test revealed a mass growing in Zain’s bladder. After a CT scan and surgery to remove the mass, doctors told Alisia that Zain had cancer.

The news was numbing. “I was shocked. I cried. I was so ashamed, because at that point I didn’t know that kids could have cancer,” she says. “I honestly thought Zain was the first one.”

**Never alone**

Alisia learned quickly that cancer was not solely an adult disease. Thousands of children develop cancer each year. Zain’s tumor, known as rhabdomyosarcoma, is the most common soft tissue cancer found in children and is slightly more common in boys than in girls. Although it can appear anywhere in the body, approximately 20 percent of all rhabdomyosarcoma cases occur in the genitourinary tract, which includes the bladder.

“When Zain started getting chemotherapy treatments at the children’s hospital in Jamaica, I noticed other kids with cancer. I was relieved, and I realized that we were not the only ones dealing with this life-threatening disease,” Alisia says.

Zain began chemotherapy treatments in February 2010. After several treatments, doctors repeated scans before deciding whether to recommend surgery or radiation therapy to remove the remaining tumor. They recommended radiation therapy, but Alisia weighed options elsewhere to ensure Zain received optimal care.

“Doctors in Jamaica do the best they can, but their resources are limited,” Alisia says.

She and her mother learned about St. Jude Children’s Research Hospital by searching online and
through word of mouth from friends. “We read about the referral process,” Alisia says. “We got everything together and took it to Zain’s doctor, who emailed doctors at St. Jude. Dr. Sheri Spunt responded.”

Rhabdo research

Sheri Spunt, MD, of St. Jude Oncology, specializes in the clinical investigation of soft tissue sarcomas.

“Patients with rhabdomyosarcoma tend to be young at the time of their diagnosis, and they have a lot of growth potential that hasn’t been realized yet,” Spunt says. “Surgery and radiation to the bladder are equally effective in curing the disease, but there were some concerns about surgery because of the location of Zain’s tumor. Fortunately, he qualified for the St. Jude RT-SARC protocol.”

Matthew Krasin, MD, of St. Jude Radiation Oncology, is principal investigator of the RT-SARC trial for pediatric sarcomas. The study’s objective is two-fold: to achieve high rates of local disease control by delivering conformal, or focused, radiation therapy to the tumor while reducing radiation exposure to surrounding tissue; and to minimize the late effects of radiation therapy in sarcoma patients.

“The local disease control for tumors like Zain’s has been excellent,” Krasin says. “Our local control rates have exceeded 90 percent. Although long-term effects have looked good so far using this focused form of treatment, the only way we truly know is to follow these children for a long time.”

Both Krasin and Spunt are also studying the late effects of radiation therapy in rhabdomyosarcoma patients.

“The work being done in the St. Jude Cancer Survivorship Division and what we eventually learn about late effects will influence how we treat sarcoma patients up front,” Spunt says. “As newer techniques become available such as proton beam radiation therapy and other methods, we’ll be able to compare long-term outcomes to determine which treatment approach is best.”

St. Jude was one of the first institutions to test the camptothecins class of drugs in children, and studies at the hospital suggested that these drugs would be useful for children with rhabdomyosarcoma. The drug irinotecan, for example, was studied extensively at St. Jude in Phase I and Phase II clinical trials and is now being tested in national pediatric rhabdomyosarcoma studies. This collaboration with other pediatric cancer centers ensures that discoveries at St. Jude reach children around the world.

Part of the team

When Zain arrived at St. Jude in November 2010, doctors used a thin, flexible scope to view the inner lining of his bladder and determine the location of his tumor. They repeated imaging and scans and reviewed his case with a multidisciplinary team of specialists.

“The benefit of having a multidisciplinary team is that we can consider all the options for our patients. In Zain’s case, we had input from the urologist, the general surgeon, the radiation oncologist, the pathologist and diagnostic radiologists,” Spunt explains. “We put our heads together and came up with our best recommendation for his treatment. Then, his mother participated in the decision-making about which option she felt was best for Zain.”

Zain started five weeks of radiation therapy on the RT-SARC trial soon after his arrival in Memphis and has now completed his planned chemotherapy regimen. Recent tests showed no evidence of cancer.

“At first I asked God, ‘What have I done to deserve this? Why my child?’ But now I understand that sometimes things happen in life for a reason,” Alisia says. “This experience has taught me so much. It has opened many doors for us, and I thank God that Zain is doing well. We recently got his scan results, and they are good. I don’t know how I can ever say ‘thank you’ to St. Jude. Since we’ve been here, it’s like a burden has been lifted off my shoulders,” Alisia continues. “It’s difficult to see children going through this, but we know what St. Jude does is wonderful.”

Zain Brown shares his No Mo’ Chemo celebration with (from left) Julie Morganelli, RN, Ambulatory Care Unit; Sheri Spunt, MD, Oncology, and Jessika Boles, Child Life.
Harvesting fruits, vegetables and herbs at the peak of freshness is a recipe for good taste, but it also offers higher nutritional value, which is important to patients and staff at St. Jude Children’s Research Hospital.

Springing from the ground like a new sapling, the idea to start a garden at St. Jude quickly germinated and has continued to grow each season.

“Mary Schuchaskie [manager of the hospital’s cafeteria, the Kay Kafe] and I shared a vision of having a garden that we could go to daily for produce and herbs,” says Executive Chef Miles McMath. “It started out as a small herb garden and grew from there with the help and support of fellow hospital employees.”

In early 2010, the St. Jude Garden began to flourish. Organizers obtained lumber, built and painted planter boxes and gathered such items as seeds, a tiller, a weed eater and hoses. The project currently encompasses 59 raised beds, a greenhouse and hoop houses for growing lettuce and tomatoes all year. The garden’s volunteers—many of whom are hospital employees—plant, mulch, weed, water and harvest crops seven days a week.

“Offering weekend and night options inspired employees to volunteer and got them excited about playing a role in this garden,” Schuchaskie says.

Having a garden on site shortens the time between harvesting and serving, which keeps the food’s nutritional value high and provides healthier fare for faculty, staff and patients who eat...
in the Kay Kafe. Serving foods from the St. Jude Garden also reduces the need to purchase large amounts of produce, which saves the hospital money.

“The fresher the produce, the better the taste,” McMath says. “But it was also important to me to show a cost savings for St. Jude. By the end of each season, I want to show that this really has given us better produce and has saved the hospital money.”

The St. Jude Garden provides a continuous supply of fresh vegetables year round.

“We focus on vegetables that we know how to take care of, that grow well in this climate, that we use most often in the Kay Kafe,” Schuchaskie says. “As the seasons and needs change, the garden changes with it.”

St. Jude is also composting fruit and vegetable trimmings from the kitchen to feed worms that will enrich the soil for future plantings.

“This garden means so much to our staff and patients because the idea was born here. It was and continues to be a grassroots effort that has been immeasurable,” McMath says. “This is also a relationship-building opportunity for the community. It not only provides a chance for people to volunteer their time, but it brings together individuals who have donated items as small as gloves, shovels and even compost. They all feel a part of this garden.”

Harvesting vegetables in the St. Jude Garden are (from top left) Kay Kafe Manager Mary Schuchaskie; volunteer Jeanie Nelson; Executive Chef Miles McMath (pictured with Schuchaskie) and Sous Chef Ernest Dickson.

The garden is sustained without the use of hospital dollars, thus providing a highly nutritious product without additional cost to the hospital. Volunteers contributed more than 570 hours last year to the project.

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Bushels of Facts

Each year, the St. Jude Garden provides approximately:

- 100 gallons of cherry tomatoes
- 300 pounds of green peppers
- 100 pounds of onions
- 200 pounds of potatoes
- 100 pounds of squash
- 150 heads of broccoli
- 150 heads of cabbage

Roughly 2,000 gallons of vegetable scraps have been composted, saving countless plastic bags and landfill space while providing rich organic matter for the garden.
Imagine realizing that a trusted security guard has burglarized your house. A similar discovery in the lab may help researchers identify novel treatments for multiple sclerosis.

In the battle against illness, the innate immune system serves as the body’s first responder. This branch of the disease-fighting immune system acts swiftly and broadly at the first hint of trouble, whether from bacteria or some other infectious agent. New evidence indicates part of that system plays a role in the disease flare-ups that are a hallmark of multiple sclerosis (MS). Such a scenario is like learning your house has been burglarized by a security guard.

Thirumala-Devi Kanneganti, PhD, of Immunology expects her work to have a happier ending. She led the recent effort that identified the pathway whose activation triggers the fresh immune assault and a new wave of symptoms for MS patients. The finding offers insight into the mechanisms involved in MS and other debilitating illnesses that stem from similarly misguided immune attacks on healthy tissue. Work is already underway to turn these findings into novel treatments for MS and other diseases.

“My dream is to find a way to block this disease and stop its progression,” Kanneganti says. “This pathway provides an opportunity to do just that and develop novel therapies that complement existing MS treatments by targeting a different part of the disease process.”

New insights into MS

That is good news for the world’s estimated 2.5 million MS patients, often young adults left to cope with this chronic, frequently debilitating illness. MS is thought to begin when a genetically susceptible individual comes in contact with an environmental trigger. The encounter stimulates production of specialized white blood cells known as T cells. In MS, those T cells target a molecule called myelin.

Myelin is essential for normal functioning of the brain and nervous system. It forms the protective insulation that surrounds nerve fibers, helping to ensure nerve impulses travel smoothly. As MS progresses and the T cells launch periodic attacks on myelin, the insulation is gradually replaced by scar tissue. Nerves can be damaged and the nervous system disrupted. For patients, it means symptoms often come and go, a process known as relapsing and remitting, along
with inflammation and the T cell assaults. The disease that begins by causing fatigue and numbness can eventually affect organs throughout the body, leading to memory problems, blindness and paralysis. Current medications target the myelin-specific T cells.

Investigators believe the initial encounter between at-risk individuals and environmental triggers is enough to launch MS and send the T cells across the blood-brain barrier meant to protect the central nervous system. But sustaining the disease requires periodic reactivation of T cells against myelin. Research led by Kanneganti and published recently in the scientific journal Immunity sheds new light on that process.

Uncovering the mastermind

Kanneganti studies the innate immune system, both how it recognizes and responds to germs and how errors in the system can trigger excessive inflammation, autoimmune attacks and other health problems. This latest advance in understanding MS began as an effort to untangle the circumstantial evidence linking MS disease flare-ups with bacterial infections.

The study builds on earlier observations that a piece of the bacterial cell wall is present in specialized regulatory immune cells found in the brains of MS patients but not in healthy individuals. The bacterial component is called peripheral peptidoglycan, or PGN. The reports were intriguing in part because immune cells called dendritic cells were shown to harbor PGN. Dendritic cells are also known as antigen-presenting cells. These cells can ramp up production and activity of T cells that target myelin and drive MS. Until now PGN’s role in the process was unclear.

Working in a laboratory model of the disease, Kanneganti and her colleagues linked the renewed immune attacks to recognition of PGN by proteins that are part of the innate immune system. The recognition sets off a biochemical cascade within the dendritic cells.

The result is a new round of inflammation in the central nervous system and new crop of T cells bent on myelin’s destruction.

“Our observations provide a mechanism by which PGN present in the brain or prior bacterial infection could contribute to MS progression. This fills a major gap in MS research and understanding,” Kanneganti says. The pathway she and her colleagues identified also offers a promising target for drug development.

Nabbing the culprit

Kanneganti’s laboratory has a long-standing interest in molecules that are key players in the pathway. Those include the proteins NOD1 and NOD2, whose recognition of PGN investigators now believe triggers the biochemical cascade that starts the renewed immune assault. Once activated, NOD1 and NOD2 work through RIP2, another molecule in the pathway, to activate the process.

In the lab, investigators showed that eliminating NOD1, NOD2 and RIP2 eased MS symptoms, but did not prevent the disease. The mildest symptoms were associated with a lack of RIP2. The findings suggest that without RIP2 dendritic cells did not recognize or respond to PGN. No recognition means no new immune assault.

Although no drugs are currently on the market that specifically target RIP2, Kanneganti says work on experimental compounds is already underway.

“I am sure we could stop MS disease progression by targeting RIP2,” she says. “Such a drug could be used synergistically with current MS treatments. A RIP2 inhibitor might also be important for treatment of other autoimmune diseases.”
Life after Cancer

For many young cancer patients, surviving a childhood diagnosis is just the beginning. Many survivors experience side effects ranging from fatigue and learning problems to obesity and second cancers.

As the population of childhood cancer survivors has grown, St. Jude Children’s Research Hospital has pioneered programs to identify the long-term impact of treatment and to provide supportive care for survivors.

Those efforts include the After Completion of Therapy Clinic, the Childhood Cancer Survivors Study and the St. Jude LIFE study. In the following pages, you’ll obtain a glimpse into a couple of specific research projects as well as meet former patients who, thanks to St. Jude, not only survive but thrive.
Mother's Day

By Elizabeth Jane Walker
Life after Cancer

determined the color of Blair Collins’ eyes, the texture of her hair, the tilt of her chin. But the legacy she bequeaths to her son and daughter will be just as important. From their mom, Tyler and Katie will learn how hope can arise from heartbreak; how adversity can spawn resilience; how faith can conquer fear.

Blair began mastering those lessons on a cold January afternoon in 1970, at the age of 3. That was the day doctors announced that she was going to die.

The darkest nights

Blair’s mom, Judy Huddleston, remembers the scene as though it were yesterday. The dire prognosis occurred at 5 p.m. on a Tuesday.

“We don’t have a cure for acute lymphoblastic leukemia,” the doctor said. “But we can help your daughter. We can give her some time—a few weeks, a few months, maybe even a year to live.”

“I remember feeling like I wanted to die,” recalls Judy, who had three other children ranging in age from 5 years to 5 months old.

But Judy didn’t die. Instead, like thousands of other St. Jude parents, she cried. She prayed. She persevered.

Doctors at St. Jude Children’s Research Hospital immediately began treating Blair with chemotherapy as well as radiation to her brain and spinal column. Only eight years before, the treatment for acute lymphoblastic leukemia (ALL) had consisted solely of chemotherapy, with only four children out of 100 surviving the agonizing regimen. Most patients who achieved remission later died when leukemia cells returned in the fluid surrounding the brain and spinal cord.

When Blair arrived at St. Jude, physicians had recently begun pairing chemotherapy with preventive radiation to the central nervous system. This combination therapy would revolutionize leukemia treatment.

Physicians admitted Blair into the hospital for 10 days. The toddler spent mornings and afternoons with her parents, lulled by the gentle sway of a rocking chair or comforted by her mom’s proximity during spinal taps, radiation sessions and innumerable needle sticks.

For Blair, the day’s discomforts were minor when
compared to the terrors of the night.

In that era, parents were not allowed to remain in the hospital after 6 p.m. Nurses told Blair’s mom that the toddler would huddle in the rocking chair all night, resolutely refusing to eat or sleep until her parents’ return.

“I was only 3, but I can remember being really sad. I wouldn’t eat my breakfast until they got there,” Blair says.

The evenings were interminable for her mom, as well. “I would come home from St. Jude and be so upset because I’d had to leave Blair behind. My arms would just ache to hold her,” Judy says, her voice cracking with pain as raw today as it was 40 years ago. “Our daughter Angie was 5 months old at the time. I’d pick Angie up gently—so as not to awaken her—and rock her in the dark while I cried and cried. Then I’d get up, put her back in the bed and slip out of her room, feeling just a little bit better.”

**Heaven can wait**

The next few years were a blur of treatments and medical challenges—colds that morphed into bronchitis, a life-threatening chicken pox outbreak and countless other crises.

“I faced the reality of death head-on,” Judy recalls. Once, during a radiation session, Judy inquired whether the treatment would affect Blair’s reproductive system. The doctor replied, “Mrs. Huddleston, we are trying to save her life. We really can’t be too concerned right now about her ovaries.”

Judy realizes that the physician was being brutally honest. In that era, few children survived ALL.

“I remember thinking, ‘But what if she lives?’” Judy says. “I was hoping for Blair to live; I was praying for it. I had to treat her as if she would survive.

“It was hard to keep hope going when you didn’t know what was going to happen and you were waiting for that relapse,” Judy continues. “So many children died. We’d go back every week and there’d be more who had passed away.”

Even though she was young, Blair was well aware that the odds were stacked against her.

“Mom and Dad prepared me for heaven,” she says. “I remember being really sick one night. I asked them, ‘Is this the night I’m going to heaven? Are you coming with me?’ Mom said, ‘I won’t come yet, but you go on if you need to, and I’ll be there soon.’ When I woke up in the morning, I’d run through the house and shout, ‘I didn’t go to heaven—I’m still here!’”

**Ah-ha moments**

Thanks to St. Jude combination therapy, Blair’s disease went into remission and she never experienced a relapse. But the treatment that saved her life also caused memory and learning issues, which tormented her throughout high school and college. Neither her teachers nor her family realized that those problems were related to her cancer treatment.

When Blair attended the hospital’s first Survivor Day, she shared her frustrations with Joseph Simone, MD, who was then director and CEO of the hospital. “I can’t do the work; I don’t know what’s wrong with me,” Blair told him. Simone explained that she had received radiation to the part of the brain that controls short-term memory. “That knowledge was very helpful,” Blair admits. “After that, my school allowed me to take my exams orally, and my grades improved.”

A few years ago, Blair attended a St. Jude seminar in which survivors were asked if they had encountered memory problems.

“Everyone in the room raised their hands,” Blair says. “I had an ‘Ah-ha’ moment. I realized that I’m not the only one who struggles with these issues.”

When Blair married, she also discovered that radiation and chemotherapy had adversely affected her fertility. She and her husband, Jeff, were heartbroken when she gave birth to a stillborn baby boy.

“It was a blessing that I got to see my son and hold him and tell him goodbye,” she says. “My faith and my
mom’s strength helped me deal with the disappointment and move forward.”

The couple’s heartbreak turned to joy with the adoption of Tyler and later Katie.

“Adoption is an amazing option,” Blair says. “Giving birth and adopting feels the same to me. I held my own little son who looked just like my husband. Then I held these little guys. There was no difference in the depth of love that I felt.”

**Helping future survivors**

Blair and her mom marvel at the drastic improvements that have occurred in cancer therapy during the past four decades. St. Jude clinicians have replaced cranial irradiation with carefully personalized chemotherapy and supportive care. As survival rates skyrocketed, physicians began designing treatments that minimized many of the side effects that plagued Blair and other patients.

By participating in one of the early ALL protocols, Blair played her part in boosting the survival rate for thousands of children around the world. Recently, she agreed to participate in a program that will help current and future survivors. Blair enrolled in St. Jude LIFE, an initiative that brings childhood cancer survivors back to campus to evaluate the long-term effects of their disease and its treatment. Not only will the study help clinicians develop safer therapies for future patients, but it also provides Blair and other survivors with individualized information about their health risks. Sometimes patients end up educating their doctors.

“Blair was in a group that received a significant dose of radiation,” observes Tim Folse, MD, of St. Jude Oncology. “A general practitioner may spend an entire career and never see a patient who has been exposed to radiation therapy as a child.”

When Blair returned to the hospital for St. Jude LIFE, she underwent an extensive battery of tests that provided further data for researchers studying the late effects of cancer therapy. At the end of her visit, Blair returned home to Virginia with a document summarizing the treatment she had received in the 1970s, her current health status, her risk for specific late effects and a schedule of suggested exams.

“Without this summary, Blair’s physician may not have known that she has a higher risk of skin cancer and that she needs a yearly skin exam,” Folse says. “She also needs an echocardiogram annually because she had chest radiation at such a young age. These are issues that many general practitioners may not realize, unless they received training at a pediatric cancer institution. The summary provides them with the details they need to provide our survivors with the best possible care.”

**Mothers and daughters**

Decades have passed, but still families come: Just as Judy did in 1970, trembling parents deposit their hopes and dreams and darkest fears on the doorstep of St. Jude.

A couple of years ago, Judy and Blair watched a distraught young woman push a stroller into the lobby of the St. Jude Patient Care Center. Judy immediately recognized the terror on the young mother’s face.

“I can’t do this,” the woman wept. “My daughter’s been diagnosed with leukemia, and my husband has left me. I’m not going to be able to make it.”

“Yes, you can do this,” Judy said. As she wrapped her arms around the young mother’s shoulders, Judy pointed to Blair. “Do you see her? That’s my daughter. She was here 40 years ago with leukemia. You can do this.”

Judy knew that, like scores of other St. Jude parents, the young mother would pray. She would persevere. And—with a St. Jude ALL survival rate of 94 percent today—she would have reason to hope.

In 1970, Blair Collins turned to St. Jude for lifesaving treatment. Today, Blair (shown with son Tyler, husband Jeff and daughter Katie) helps other survivors through participation in the St. Jude LIFE study.
Researchers discover that breast-feeding may ease some late effects of childhood cancer treatment.

BY ELIZABETH JANE WALKER

When Emily Miller Land delivered a son in March of 2008, she had already identified breast-feeding as a healthy option. But Emily did not appreciate just how important that activity might be to cancer survivors like herself.

“I knew it would help me lose weight a little bit faster and that it was supposed to be good for my bones,” says Emily, who received treatment for the bone cancer osteosarcoma at St. Jude Children’s Research Hospital.

Justin’s premature arrival reinforced Emily’s determination to provide him with the best possible nourishment.

“Breast-feeding was something I had planned to do anyway,” she says, “but I had this compelling urge to do everything I could to help Justin get out of the hospital.” She immediately began pumping breast milk for her 3½-pound infant. Today, Justin is a delightful toddler who speaks two languages and amazes his parents with his accomplishments.

Emily is grateful that she was able to provide her son with a nutritional option that helped him thrive. But she recently learned that the activity may have offered extra benefits to her own health. According to new St. Jude research, breast-feeding may help ameliorate many of the problems encountered by pediatric cancer survivors.

A happy coincidence

Thanks to advances in cancer biology and treatment, the survival rates for childhood cancer have increased exponentially in the past few decades. But few survivors have emerged unscathed. Almost all of them have an increased risk of significant health problems ranging from obesity to early-onset osteoporosis. Survivors also experience high rates of heart disease, diabetes and
Life after Cancer

Wouldn’t it be great if one simple activity could help alleviate those risks? St. Jude researchers found that breast-feeding may do just that.

“We know that breast-feeding protects babies,” says Susan Ogg, RN, a research nurse in St. Jude Epidemiology and Cancer Control. “But it also protects moms in wonderful ways.”

Not only does lactation boost metabolism—helping a new mother burn up to 500 extra calories per day—but it also has a positive effect on her calcium reabsorption after the baby is born. Breast-feeding has been shown to reduce maternal stress and postpartum depression, as well as decrease a woman’s risk of developing diabetes and high cholesterol.

Of particular interest to childhood cancer survivors is the fact that breast-feeding reduces their risk of breast, uterine and ovarian malignancies.

“It just so happens that breast-feeding benefits many of the same systems that are adversely affected by cancer treatment,” says James Klosky, PhD, of St. Jude Psychology. “We’re not saying that it’s the cure-all for the late effects encountered by childhood cancer survivors, but it appears reasonable that the benefits of breast-feeding in the healthy population should generalize to the childhood cancer population.”

Challenges for survivors

Klosky and Ogg study the issues surrounding lactation and survivorship. Among their findings, published recently in the Journal of Cancer Survivorship, is the realization that many childhood cancer survivors are physically unable to breast-feed.

Former St. Jude patient Victoria Boren is one of those survivors. After undergoing treatment for acute lymphoblastic leukemia (ALL) at St. Jude, Victoria encountered late effects ranging from chronic fatigue syndrome and fibromyalgia to cardiomyopathy, an enlarged heart. Because the medicine Victoria required to treat her heart condition might pass through her breast milk to her infant, doctors discouraged her from nursing her son, Parker.

“I had been planning on breast-feeding because it makes the mom and baby healthier,” she explained. “I knew it would boost Parker’s immune system, would help us to bond and would help prevent postpartum depression. I was disappointed that I couldn’t do it. I definitely hope to breast-feed if we have another baby.”

Other childhood cancer survivors sometimes discover that the surgery or radiation used to cure their disease may have damaged their pituitary glands or caused other issues that affect lactation. In an Australian study of women who received high-dose cranial irradiation for the treatment of childhood ALL, only 17 percent were able to breastfeed their children. In another study, 66 percent of Hodgkin lymphoma survivors reported successful lactation.

Baby, oh baby!

Ogg emphasizes the need to educate community physicians about the advantages of breast-feeding as well as about the lactation challenges experienced by some cancer survivors. Most of the benefits to infants are well known: Breast-fed babies have a lower risk of sudden infant death syndrome, infections and conditions ranging from asthma and obesity to diabetes. But many parents are unaware that infants who are breast-fed for more than six months have a significantly lower risk of ALL, Hodgkin lymphoma and non-Hodgkin lymphoma, as compared to babies who were not breast-fed.

“Moms who have survived childhood cancer do not want their children to go through what they endured,” Ogg says. “Anything they can do to protect their children is psychologically beneficial to the survivors. It makes them feel like they’re empowered to help their children avoid some of the same disease processes that they had to suffer.”

Klosky and Ogg are already pursuing further research on the topic. They are interested in exploring whether women who had specific types of treatment are at significantly increased risk for lactation problems. In addition, the team wants to examine the specific physiological changes that occur in mothers who have breast-feeding challenges. A retrospective study within the St. Jude After Completion of Therapy Clinic will allow women to report their experiences. Plans are also in the works to educate primary care providers about the risks faced by adult survivors of childhood cancer.

Klosky says that this research has implications for cancer survivors around the globe. “If you’re a mother, breast-feeding is something that has benefits, but no known risks,” he says. “It’s something that you may be able to do—regardless of whether you live in India or China or Argentina. There’s really no down side to it, and the benefits are numerous. So why not try it?”
Just before you drift off to sleep tonight, think about Quay West. Odds are, she’s wide awake.

Quay, a survivor of Hodgkin lymphoma, suffers from insomnia. Ironically, her inability to sleep has nothing to do with the fact that she manages a college residence hall, where students come and go at all hours of the night.

“My sleep and fatigue problems began 25 years ago,” says Quay, who underwent treatment for her cancer at St. Jude Children’s Research Hospital. “They started even before I went through chemotherapy, but they’ve gotten progressively worse. There have been weeks that I’ve gone three or four days with just an hour or two of sleep. The worst was five days with maybe an hour of sleep.”

Scientists have long acknowledged that many childhood cancer survivors experience marked fatigue and poor sleep quality. When compared with healthy members of the population, cancer survivors also

St. Jude scientists discover that childhood cancer survivors are particularly vulnerable to the effects of fatigue and sleep deprivation.

BY ELIZABETH JANE WALKER
experience more trouble with mental processing speed, attention, reasoning and memory.

Until recently, scientists did not know that survivors were particularly vulnerable to the impact of fatigue and sleep quality on memory, organizational skills, emotional control and task efficiency. Kevin Krull, PhD, of St. Jude Epidemiology and Cancer Control, and his colleagues led a study revealing that connection. Results of their research recently appeared in the journal *Cancer*.

**Cognitive challenges**

The study involved 1,426 childhood cancer survivors and 384 healthy siblings enrolled in the Childhood Cancer Survivor Study (CCSS). Headquartered at St. Jude and funded by the National Cancer Institute, the CCSS now encompasses 30 collaborating institutions located throughout the United States and Canada.

Cancer survivors who have undergone radiation therapy to the brain or who have received chemotherapy that affects the brain have an increased risk of cognitive problems. Krull and his team discovered that fatigue and sleep impairment exacerbates those issues for all survivors, regardless of the type of cancer therapy they received.

“If you or I miss some sleep for a while, we may be able to deal with it, compensate and muster the resources to function adequately,” Krull says. “Cancer survivors have much more difficulty with that.”

Krull and his colleagues discovered that survivors with sleep problems had a three- to four-fold higher risk of attention and memory impairments than their siblings did. The childhood cancer survivors also indicated slower cognitive processing speed and more difficulty regulating their emotions.

Like an irritating bee that buzzes just outside of her reach, the most basic words often elude Quay.

“One day, I couldn’t think of the word ‘truck,’” she says. “I was sitting there with the mental image of the vehicle, but I couldn’t get the word ‘truck’ out. I attributed it to my fatigue.”

**Re-collecting recollections**

Scientists have begun to design new therapies and interventions to help individuals like Quay. Krull says survivors may benefit from periodic screenings of their sleep habits and fatigue levels. Survivors may also benefit from memory training, a skill-based approach that allows them to repeatedly practice getting details into their memory and then retrieving that information.

The hospital has an ongoing study to determine whether Web-based skill training may help survivors improve memory and attention functions. Participants are also provided instruction on strategy techniques that include using memory notebooks; employing simple organizational strategies such as putting keys in the same place every day; and repeating facts until they are lodged in memory and can be retrieved.

Krull also points out that some survivors may benefit from intensive aerobic exercise. St. Jude is designing an exercise intervention to determine whether exercise may help to improve memory function in cancer survivors who are at risk for those difficulties. Researchers are also looking at biomarkers in fatigued survivors to see if they exhibit signs of inflammation.

A couple of years ago, Quay returned to the hospital to participate in the St. Jude LIFE study, which studies the long-term effects of cancer and its treatment. Physicians talked with her about the importance of exercise, especially for those who suffer from insomnia.

“Exercise does seem to make me feel and think better,” Quay observes. “My cancer treatment affected my heart, so I can’t do anything super-strenuous. I do weight training, and I walk and work out on the elliptical machine. But because of the lack of sleep, sometimes I don’t have the energy at the end of the day to exercise.”

**Sweet dreams**

Krull and his colleagues are also planning a new intervention that includes what he calls sleep hygiene, or activities that promote and encourage sleep. By helping patients fall asleep and improve their sleep quality, the researchers hope to improve survivors’ cognitive function as well.

Activities may be as simple as avoiding caffeine after noon, exercising before 5 p.m., ensuring proper nutrition, taking a warm bath and avoiding reading or watching TV in bed.

“We’ve already developed sleep hygiene educational materials that we put on our website and that we provide to our adult population in our St. Jude LIFE study,” Krull says. “We provide this educational component as a standard of care for those who are having cognitive problems and are reporting sleep difficulties.”

Quay hopes those kinds of interventions will help her.

“The insomnia and fatigue have most definitely affected my memory and organizational skills,” she says. “I never finished college because of that. If I could find a way to go to sleep naturally, that would be awesome. Then I could think about going back to school and finishing my degree.”
When the Carnival Magic cruise ship set sail on her inaugural voyage May 1, the ship carried some special St. Jude VIPs—former patient Lindsey Wilkerson and her family.

To honor the patients and the mission of St. Jude, Carnival chose Wilkerson to be godmother of the new ship. She officially named the Carnival Magic during a shipboard ceremony prior to its first voyage from Venice, Italy, to Barcelona, Spain.

“Lindsey embodies the spirit of the tremendously talented, compassionate and dedicated individuals at St. Jude who are true heroes in every sense of the word. Lindsey’s selection as godmother is a tribute to the special children of St. Jude, as well as an acknowledgement of the groundbreaking efforts the organization has made in the fight against childhood cancer,” says Gerry Cahill, Carnival president and CEO.

Wilkerson’s selection continues a dedicated partnership with Carnival that began last year when the cruise line launched its Care to Play: Carnival for St. Jude Kids program. Guests aboard all ships in Carnival’s fleet can participate in fun activities to help raise awareness and funds for St. Jude and the fight against catastrophic childhood diseases.

Carnival made a $50,000 donation to St. Jude in Wilkerson’s honor during the naming ceremony and has set a goal to raise $3 million in three years for St. Jude through Care to Play.

“On behalf of all of the children of St. Jude, I’m so honored to serve as godmother to the beautiful Carnival Magic and celebrate this exciting opportunity,” Wilkerson says. “I am alive today because of the world-class research and treatment at St. Jude. The generous support of Carnival and their guests will help St. Jude continue to provide hope to children stricken with catastrophic illnesses.”

Wilkerson was 10 when doctors discovered that she had cancer. Her treatment was successful, and she has continued to inspire others with her story of hope. In 2004, she began working for ALSAC, the fundraising organization of St. Jude, supporting volunteers across the country as a volunteer specialist. She also serves as a tour guide at the hospital, as president of the St. Jude Women’s Club and as a member of the hospital’s Family Advisory Council.

“Carnival has been very creative in developing entertaining fundraising opportunities for guests through its Care to Play program,” said Richard C. Shadyac Jr., CEO of ALSAC. “We were so excited when we heard that they selected as godmother of the ship one of our former patients, Lindsey, whose story touched not only our friends at Carnival, but so many others who have had the pleasure of meeting her. She is a true inspiration to us all.”

Learn more about the partnership between Carnival and St. Jude and donate to the Care to Play program at www.carnival.com/stjude.
Long before graduating with honors from Georgetown University and working alongside his father, Donald Trump, Eric Trump recognized that having a renowned surname comes with great responsibility and opportunity.

“I had been given everything in life. I drew the long straw in health, and I was incredibly lucky to get a great education,” says Eric, 27, executive vice president of Development and Acquisitions for The Trump Organization.

So at age 22, he did something that few young men of his generation do: He brainstormed with like-minded friends about ways to give back to the community. “We decided we wanted our focus to be on children because that was most near and dear to our hearts,” he says.

The result was The Eric Trump Foundation (ETF), whose events have benefited St. Jude Children’s Research Hospital since 2007. The foundation board visited many children’s hospitals before choosing St. Jude as its sole beneficiary.

“We were moved by what we saw when we went to Memphis and toured the hospital. They have a recipe for success unlike any other hospital,” Eric says. The selling point for him was that St. Jude never denies a child treatment due to the family’s inability to pay or charges families for what their insurance does not cover.

A self-described “numbers guy,” Eric says the hospital’s success is quantifiable. “To me, it is all about basic numbers. In the 1960s, the survival rate for acute lymphoblastic leukemia was 4 percent; today it is 94 percent,” he says.

He also cites the hospital’s work in retinoblastoma, a disease for which survival rates have increased from 75 to 95 percent. “One doctor, in perpetuity, can make a tremendous difference and save thousands of lives,” he observes. “They are miracle workers.”

Eric wanted his foundation to be a similar model of efficiency. By leveraging Trump Organization resources, Eric gets everything gratis for events. He credits a dedicated board for the success of the foundation, which has increased its donations almost 40 percent year after year while maintaining one of the lowest expense ratios in the country. “We have an incredible team,” he says, mentioning board member Katrina Kaupp, in particular.

Eric is also a member of the St. Jude Professional Advisory Council, a group he admires for its diversity and commitment. “They really believe,” he says. “They are industry leaders who, like me, are willing to move mountains for St. Jude.”

The main fundraiser for ETF is a golf invitational held every September at Trump National Golf Club, Westchester, New York. With plans to expand this successful franchise to all Trump National Golf Clubs within the coming years, Eric is confident ETF will be able to raise more than $1 million for St. Jude annually.

Every year when Eric visits St. Jude, he meets a patient family. During his first visit, he met a boy who had little hope for survival. Last year, the family attended the ETF golf invitational, where the boy and his parents received a standing ovation from the more than 700 attendees.

“We have become great friends with the family,” Eric says. “They are amazing people.”
People working in any aspect of cancer research, not just childhood cancer, know of St. Jude Children’s Research Hospital for its landmark work. The hospital’s founder, Danny Thomas, not only created an organization that generated funds to do what was seemingly impossible; he also ensured that scientists and the hospital administration could look out for the science and do what they thought was best.

Some of the best science is moved ahead when scientists present their research to other interested scientists, who then ask questions and offer feedback. That’s why the hospital created the Scientific Advisory Board. This diverse group consists of 14 scientists who have a clear interface with research occurring at St. Jude. I currently chair this group; our goal is to provide insight and feedback to the St. Jude Board of Governors about the hospital’s research. We also provide specific recommendations for activities that the hospital might want to consider as it tries to improve what it is already doing so well.

At the University of Wisconsin, my work is dedicated to trying to do better cancer research. A component of that has a focus on childhood cancer. When I interact with scientists who have similar interests, I learn information that can help me do a better job in my own work. Every time I come to St. Jude, I learn something important about new ideas, new research, new things that are being done.

The field of childhood cancer research can’t be secretive. St. Jude knows that and puts it into practice. Ideas and data must be shared so that researchers in other places can learn from those advances and use the information. That’s crucial, as dedicated scientists around the world work to move cures ahead as quickly as possible.

All members of the Scientific Advisory Board understand what an incredibly special resource St. Jude is to the world. One of the hospital’s many strengths is its outstanding research infrastructure, enabling it to link complex laboratory and clinical research together in order to improve clinical care worldwide.

Those of us who are on the Scientific Advisory Board are pleased that a place like St. Jude exists. It’s an honor to be able to come to the hospital and learn. Even though our own jobs are at other institutions, we are in some way helping St. Jude to be even better—and to continue to be a resource to the rest of the world.

St. Jude Scientific Advisory Board Chair Paul Sondel, MD, PhD, is the Walker Professor of Pediatrics, Human Oncology, at UW Carbone Cancer Center and American Family Children’s Hospital, University of Wisconsin.
Since 1962, St. Jude Children’s Research Hospital® has helped children like Bill in the fight of their lives against cancer and other deadly diseases. Thanks to support from friends like you, St. Jude has grown into one of the world’s premier pediatric cancer centers. Our patient care is unsurpassed, and because our groundbreaking research is freely shared, it can reach children in communities around the world.

You can make the difference of a lifetime with a legacy gift to St. Jude through your estate plans. Your legacy will help St. Jude continue its lifesaving mission so that one day all children with cancer can realize their dreams.

Call us at 1-800-395-1087 or visit us online at www.stjudelegacy.org.
Pomp and challenging circumstances

Riley Wilson and 26 other students celebrated an important milestone in May when they participated in the hospital’s fourth annual kindergarten graduation. The St. Jude School Program presented by Target helps patients like Riley continue their normal educational activities while they are undergoing treatment.

“Many patients miss their own graduations, so this helps fill that void,” says Michaela Shurden, kindergarten–6th grade teacher. “One patient this year was newly diagnosed just days before our graduation, which also happened to be the same day hers was going to occur at home. Both the parents and the patient were thrilled and appreciative that she was able to participate in graduation after all.”

The school program also hosts high school commencement exercises in collaboration with Child Life. This year, 13 teens participated in the high school commencement.