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MORE THAN
Skin Deep

Through clinical trials and a revolutionary genome project, St. Jude clinicians and researchers unveil the secrets of childhood melanoma.

The young girl’s fair skin, freckles and luxuriant red hair originated with her Dutch ancestry. The boy’s darker complexion is the result of his Filipino and African-American heritage. But 10-year-old Alyssa de Jong and 9-year-old Asa Boomer-Brazier share a disease more frequently associated with Caucasian adults: a malignant skin cancer called melanoma. Both Alyssa and Asa owe their lives to parental vigilance and the superb medical care they have received at St. Jude Children’s Research Hospital.

Melanoma occurs so rarely in young children that pediatricians may miss it during routine checkups.

“When a mole appeared on Asa’s shin in the fall of 2012, his pediatrician sort of dismissed it,” says his mom.

During the three-month wait to see a dermatologist, Asa’s mole grew. And grew.

By the time a definitive diagnosis occurred, the little boy had an advanced form of pediatric melanoma, which can be life threatening. His mom, university biostatistician KB Boomer, immediately began researching the subject. “I read every scientific article I could find on pediatric melanoma,” she recalls.

KB quickly realized how unusual it is for young children to have the disease. Although skin cancer is the most common form of cancer in the U.S., fewer than 70 cases of melanoma occur annually in
individuals under age 10. And only 10 to 15 percent of those children have an advanced form of the disease, which means it has spread to the lymph nodes or other parts of the body.

When Alyssa’s mom learned that the red bump on her daughter’s arm was melanoma, she was shocked. “That can’t be!” Angela told the dermatologist. “You told me that doesn’t happen in kids under 13!”

But it does.

“A lot of pediatricians and family doctors simply don’t think about melanoma occurring in children,” says Fariba Navid, MD, of St. Jude Oncology. “After all, kids haven’t had the years of sun exposure that adults have had.”

**Skyrocketing numbers**

According to the National Cancer Institute, nearly 76,700 people will be diagnosed with melanoma in 2013. Although the number of children with the disease is small, the incidence rises dramatically with age and cumulative exposure to ultraviolet rays.

“The incidence of adult melanoma is skyrocketing,” Navid says. “And it turns out that in the adolescent population, it’s also on the rise.

In the 15- to 19-year-old age group, it’s three times more common than it was 10 years ago. We think the incidence is increasing in teenagers partly because so many of them are going to tanning booths.”

In 2009, the International Agency for Research on Cancer determined that indoor tanning devices are as likely to cause cancer as cigarettes and asbestos—with melanoma risk increasing 75 percent in people who begin using tanning beds before age 30. Navid and her colleagues are doing their part to encourage patients and families to reduce their exposure to...
UV radiation, whether from sunlight or indoor tanning devices.

**Melanoma on trial**

For decades, St. Jude scientists and clinicians have been working to improve melanoma treatment. A recently completed clinical trial, headed by Navid, was the first study to use a medication called pegylated alpha-interferon in children with high-risk melanoma.

Asa was one of 30 patients to take part in that study, which included surgery to remove the lesion and any affected lymph nodes, plus treatment with a new formulation of interferon. Navid says preliminary results indicate the drug was well tolerated by study participants. Headaches and fatigue were the only side effects mentioned by Asa, who continued participating in gymnastics competitions and taking care of his pony while undergoing treatment.

St. Jude is offering three clinical trials for children with advanced melanoma:

- **One study involves an antibody that seek outs and destroys specific cancer cells.** This trial is open to patients with recurrent neuroblastoma, osteosarcoma or melanoma.

- **Another study is offered to certain melanoma patients who have a mutation in the BRAF gene.** A new medicine has been designed to target the BRAF mutation, which is involved in about half of all melanomas.

- **A third trial is studying a drug called ipilimumab.** “Normally, your immune system has brakes to prevent it from going crazy,” says Alberto Pappo, MD, of St. Jude Oncology. “Ipilimumab inhibits those brakes and lets your immune system kill the melanoma.”

In April, 15-year-old St. Jude patient Trevor Palazzo became the first person in the U.S. to enroll in the ipilimumab trial. “We’re really excited about it,” says his mom, Sherry Manuel.

**Sifting the genome for clues**

Using next-generation whole genome sequencing, scientists involved with the St. Jude Children’s Research Hospital–Washington University Pediatric Cancer Genome Project are working to understand the genetic mistakes that underlie the development and growth of melanoma. Researchers hope this project will lay the foundation for improved diagnostic testing as well as more effective melanoma therapies.

“He and Navid have teamed up with Armita Bahrami, MD, of St. Jude Oncology visits with Alyssa de Jong during a checkup.
Pathology; Howard Hughes Medical Investigator Michael Dyer, PhD, of St. Jude Developmental Neurobiology; and scientists at Washington University in St. Louis to examine three subtypes of pediatric melanomas: one that is identical to adult melanoma when viewed under the microscope; a different one that arises in large moles that are present at birth; and a Spitzoid melanoma, which is a type of melanoma that is difficult to diagnose.

Preliminary analysis of the data has revealed distinct genomic signatures for each melanoma subtype. “Melanoma has the largest number of mutations of any of the pediatric cancers sequenced thus far in the Pediatric Cancer Genome Project,” Bahrami says. “The number of mutations is just mind blowing.”

The researchers hope to complete their investigation and publish their findings within the next few months.

**Spreading the word**

When Navid and Pappo offer advice about sun safety, some patients—like Asa, Alyssa and Trevor—take those lessons to heart. They dutifully cover their skin with sunscreen, long sleeves and hats and try to avoid going outdoors when the sun’s rays are strongest.

“I’ve always been the mother who put sunscreen on my child,” observes Asa’s mom. “People would say, ‘Why are you putting sunscreen on a black kid?’ and I’d say, ‘Because everyone can get sun damage.’

“It’s important to get the word out,” she continues. “People need to know that kids can get melanoma.”

Alyssa enlists her family, friends and classmates to help her remember to wear her hat and sunscreen and keep her arms and legs covered. She wears sunscreen head to toe—even underneath her clothing and on cloudy days. She knows it’s a habit she must follow for the rest of her life, rain or shine.

“People don’t take melanoma as seriously as they need to—especially in kids,” says Alyssa’s mom. “That scares me. What if? What if we hadn’t taken Alyssa to the doctor? What if I hadn’t said, ‘Look at this!’ What if, when the doctor dismissed my concerns, I had not said, ‘This is not right’? What if we hadn’t come to St. Jude?”

Thanks to her experience, Angela has become a vocal proponent of sun safety and of the importance of continuing melanoma research. She and Alyssa recently traveled to Washington, D.C., to represent St. Jude at the Children’s Hospital Association’s Family Advocacy Day. There, Angela shared Alyssa’s story with lawmakers on Capitol Hill.

“I want to give back,” Angela says, “because this place saved my child’s life.”

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**MELANOMA:**

**Early diagnosis is key**

Melanoma is the most common skin cancer in children.

The **ABCDEs** of melanoma are used to identify melanoma in adults:

- **A** symmetry, with half of the mole unlike the other
- **B** order uneven or blurred
- **C**olor variation from one area to another
- **D**iameter bigger than a pencil eraser
- **E**volution, a change in shape, size or color

**But**

Pediatric melanoma might not fit into those categories. Look for:

- A mole that **changes**, **grows** or **doesn’t go away**
- An **odd-shaped** or **large** mole
- A **pale-colored** or **red bump**
- A mole or bump that **itches** or **bleeds**

Be persistent. Early identification and removal of melanoma is critical.

Learn more: [www.stjude.org/melanoma](http://www.stjude.org/melanoma).

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Fifteen-year-old St. Jude patient Trevor Palazzo—pictured with his oncologist, Fariba Navid, MD, of St. Jude Oncology—was the first person in the U.S. to enroll in a new clinical trial for adolescents with stage III or IV melanoma.
Children of any ethnicity can be struck with acute lymphoblastic leukemia (ALL), the most common type of pediatric cancer. But scientists have long known that Hispanic children are at higher risk of developing ALL than white or African-American kids.

The reason for this discrepancy has remained a mystery. But scientists at St. Jude Children’s Research Hospital have recently started to uncover some important clues, buried deep within the DNA that children inherit from their parents.

“For many years, people suspected that there was a genetic basis to susceptibility for ALL,” says Jun Yang, PhD, a lead researcher in the recent work. “For example, in identical twins with the same genetic makeup, if one twin has leukemia, the risk of the second twin developing it is much higher.”

However, Yang says, it has been challenging to find the subtle DNA differences that make children in some ethnic groups more likely to develop ALL.

Unexpected risk

To search for these differences, Yang and his collaborators painstakingly combed through the DNA of thousands of children with ALL, comparing their entire genetic makeups to those of individuals without ALL. The scientists were trying to find small variations that could account for differences in disease risk.

What they discovered was striking: For all ethnic groups, inheriting high-risk versions of just four genes was associated with up to a ninefold higher risk of developing childhood ALL. The degree of increase in risk was unexpected for a complex disease such as ALL.

“It’s only four variants, and putting them together gives such a large effect; it’s pretty impressive,” Yang says. “I was a bit surprised at that.”

And the researchers made another key finding: Two of the high-risk gene versions were more frequently inherited by Hispanic children, pointing to at least one reason for their increased odds of developing ALL. Furthermore, St. Jude scientists have found one potential reason why Hispanic children have a higher risk of developing acute lymphoblastic leukemia when compared to African-American or white children.
these versions were least common in African Americans, who have the lowest disease risk.

“This was the first multi-ethnic, genome-wide study of this size to look at risk factors for pediatric ALL,” Yang says. “Unless we study minority populations, we just won’t know what is driving the ethnic disparity in this disease.”

Tailoring therapy

Finding these risk factors is a first step toward creating new treatments tailored for individual ALL patients based on their genetic makeup. But with 94 percent of St. Jude ALL patients already becoming long-term survivors, how much better can therapy become?

“ALL is a tremendously successful story in our battle against cancer,” Yang says. “However, the conventional chemotherapy we use on young patients can be ‘big cannons’ with a lot of side effects.

“What we need to do next is to develop more precise, targeted therapy for leukemia. And how do we do that? We need to learn more about the biology of the disease,” he continues.

“Now we know that these genes are important, which tells us a lot about the process by which leukemia actually develops. And that gives us a hint as to what we should be targeting with new therapies.”

Debt of gratitude

The collaborative research environment at St. Jude was key to the success of this large-scale endeavor.

“We had extensive collaboration within St. Jude—biostatisticians, pathologists, oncologists and scientists who are studying leukemia biology and pharmacogenomics,” Yang says. “We also reached out to the Children’s Oncology Group, which treats pediatric cancer patients around the country.”

And, he adds, there were other collaborators with a vitally important role.

“None of this could have happened without the patients and their parents,” he says. “They are extremely generous, working with us to help the research move forward. They understand how important the work is—how it can help not only children undergoing treatment, but also future patients.”

An event that occurred early in Yang’s research career continues to provide him with motivation.

“I was giving a laboratory tour once and met a St. Jude patient with a brain tumor, who said she wanted to do research someday to help other kids,” he recalls.

“As they were leaving, her mom came up to me and held my hand. She said, ‘I pray every day that you get to do the work you’re doing, because that is the only hope for my child.’

“It was emotional,” Yang says, “and I understood more than ever the importance of the work we do at St. Jude.”
UNANTICIPATED
Connections
How does understanding Lou Gehrig’s disease help fight childhood cancer?

“If you broaden your scope and define your research on the basis of fundamental questions about the biology of disease, it can yield some unanticipated connections,” says J. Paul Taylor, MD, PhD, shown working with colleague Amandine Palud.

By Joyce M. Harris and Carole Weaver

Developmental neurobiologist J. Paul Taylor, MD, PhD, thrives in an environment that promotes stellar science. And it never hurts to throw in a healthy dose of serendipity.

In pinpointing rare genetic mutations involved in motor neuron diseases, he and his colleagues at St. Jude Children’s Research Hospital made a stupendous realization; their findings also uncovered clues essential to understanding a molecular mystery.
that has eluded cancer experts for more than a decade. “Five or 10 years ago, nobody would have imagined that the gene families involved in motor neuron diseases were similar to genes involved in childhood sarcomas,” Taylor says.

This finding is the latest in a series of discoveries suggesting that degenerative diseases and cancer may have common origins.

### Power of the genome

Finding new, rare genetic changes involved in motor neuron diseases was a Herculean task, made possible only by the powerful technology available at St. Jude.

“Years ago we found disease genes the ‘old-fashioned’ way,” Taylor says. Progress was limited because researchers needed to study large families to make a connection between a disease and a specific genetic change.

Then along came a game-changer: a new type of technology called high-throughput genome sequencing, available as part of the St. Jude Children’s Research Hospital – Washington University Pediatric Cancer Genome Project (www.stjude.org/pcgp).

“The technology brought to St. Jude by this project enabled us to start finding these genes,” Taylor says. “This discovery would not have been possible without the Pediatric Cancer Genome Project.”

### An important domain

It was only in the nuts and bolts of the discovery that the connection to cancer became clear. To find the culprit mutations, Taylor’s team scrutinized the genomes of several families with motor neuron diseases and found two rare mutations not previously linked to amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig’s disease. The genetic changes altered a region or domain found in specific types of proteins that help deliver genetic instructions within cells.

Abnormalities in this type of protein domain have also been found to be responsible for most cases of Ewing sarcoma, a bone cancer that occurs in children and adolescents. However, it was a mystery what the protein domain normally does inside cells, an essential piece of information for understanding its role in disease.

“The normal function of the domain was critical for us to determine, because it is the key to understanding ALS, and it is the key to understanding sarcomas,” Taylor says.

What his team found was surprisingly simple. The domain, now known as a prion-like domain, normally allows proteins to clump together to perform their duties in cells and then disperse when the job is complete. But in cells with the disease-causing mutations, the proteins continue to accumulate instead of being disassembled.

In ALS, the mutation appears to cause a blockade of the chemical and electrical signals that control muscles in the limbs and torso, and muscles that control speech and breathing. The disease causes paralysis and is usually fatal within five years of diagnosis.

The discovery makes St. Jude the first to reveal the function of the prion-like domain in proteins associated with many diseases.

### Looking ahead

Armed with the new insights, St. Jude researchers are now investigating exactly how the mutations in this domain drive cancer.

“This is an exciting time. It is conceivable that if we find a drug that disentangles these prion-like domains, not only would that be beneficial for blocking ALS, but the same drug would be used to treat children with Ewing sarcoma,” Taylor says.

He is collaborating with St. Jude colleagues to connect the dots.

“We want to take full advantage of molecular-targeted therapies for pediatric solid tumors,” says Howard Hughes Medical Investigator Michael Dyer, PhD, of St. Jude Developmental Neurobiology. “Integrating laboratory-based research with clinical research is essential to raising the survival rates for children with these cancers.”

Discoveries that cross the boundaries between childhood and adult diseases can occur seamlessly at a place like St. Jude, where scientists and clinicians collaborate to understand the foundations of disease processes.

Basic research like Taylor’s is necessary to underpin future progress.

“This exemplifies the importance of fundamental research,” he says. “A narrow research focus may only offer limited opportunities for insight into what’s causing disease. If you broaden your scope and define your research on the basis of fundamental questions about the biology of disease, it can yield some unanticipated connections.”
Once again, Brayden Shields is in the driver’s seat. Today’s vehicle is a late-model desk chair, although he has been known to commandeer a sporty little laundry basket.

By Elizabeth Jane Walker

St. Jude offers children with eye cancer the specialized care they need to envision a world beyond cancer therapy.

Imagine
“Get in!” the 3-year-old urges his mom, as he fastens an invisible seat belt. Misty Shields dutifully climbs into the passenger’s seat. Their excursion culminates at Brayden’s favorite destination: St. Jude Children’s Research Hospital.

**Mother’s intuition**

Brayden was born with a rare eye cancer called retinoblastoma. The first sign of a problem occurred the moment Misty held her infant son in the delivery room.

“I told my husband that something was wrong with Brayden’s eyes,” she recalls. “They seemed to jitter and drift away from each other.”

Misty and Drew continued to worry about their son’s eyes. When Brayden was 7 months old, the pediatrician referred him to an ophthalmologist, who discovered large tumors. The physician warned that both eyes might have to be removed.

“If it were your kid, where would you take him for treatment?” Misty asked.

“I’d send him to Memphis,” the physician replied.

**One less stressor**

Within 24 hours, the Shields had obtained a referral and were walking through the doors of St. Jude. Soon, the family made an astounding discovery.

“At one point, Drew pulled out his insurance card and asked if the hospital bills would be sent to our house while we were in Memphis,” Misty recalls. “The lady said, ‘Oh, you won’t be getting a bill from us.’ She told us that they would also pay for transportation, would give us a place to stay and would pay for our food while we were here. It was just crazy.

“She was our Danny Thomas at that moment,” Misty continues, alluding to the founder of St. Jude. “We began crying, and we probably said ‘thank you’ at least 100 times.”

**It takes a team**

Retinoblastoma treatment requires a multispecialty team of experienced clinicians and researchers.

With three large tumors in his left eye and two in his right, Brayden had already lost much of his vision. Treatment would require an intensive collaboration among a cadre of specialists, including oncologists, surgeons, radiation oncologists, ophthalmologists, occupational therapists and the hospital’s genetic counselor.

“In treating retinoblastoma, we have three main objectives,” explains Brayden’s oncologist, Ibrahim Qaddoumi, MD. “Our first objective, of course, is saving the child’s life. The second objective is to avoid

**Retinoblastoma signs and symptoms**

Although Brayden did not display this symptom, a white glow called leukocoria may appear in flash photos of many children with retinoblastoma. Other symptoms can include:

- Poor vision
- Different iris color in each eye
- Both eyes turned inward or outward
- Eyes that do not point in the same direction
- Pain, redness or irritation of the eye
removing the eye. And our third objective is saving as much vision as possible.”

St. Jude deftly bridges the gap between laboratory findings and the application of that knowledge in the clinic. Discoveries made in the Developmental Neurobiology lab of Michael Dyer, PhD, for instance, have identified potential targeted therapies that kill retinoblastoma cells more efficiently than compounds used in the past. These drugs may dramatically impact the treatment of patients such as Brayden and other children with retinoblastoma.

As the toddler received his chemotherapy in the hospital’s Medicine Room, Dyer, a Howard Hughes Medical Institute investigator, and his colleagues were collaborating to make additional discoveries to further improve retinoblastoma treatment.

Eradicating the seeds

In addition to the large tumors in his eyes, Brayden developed numerous small masses called vitreous seeds, which form when portions of larger tumors break away and float within the eye’s vitreous fluid.

The little boy received 11 cycles of chemotherapy, plus frequent evaluations under anesthesia. In conjunction with chemotherapy, St. Jude ocular oncologist Matthew Wilson, MD, treated Brayden’s eyes with a combination of laser therapy and cryotherapy, which uses a probe to freeze the tumor. Brayden underwent 26 laser therapy treatments and 24 cryotherapy treatments during a two-year period.

He also received a type of highly focused radiation treatment called brachytherapy, in which Wilson implanted radioactive plaques into Brayden’s eyes. For approximately 80 hours, the small disks delivered a prescribed dose of radiation only where it was needed, preventing radiation exposure to Brayden’s brain and surrounding tissues.

“Brayden navigates his environment so well that you’d never even know he’s visually impaired,” says Tracy Douglas, Brayden’s longtime nurse practitioner.

“Like many other children who come to us, Brayden required the full gamut of services that only a multispecialty team can provide,” Wilson says. “This collaboration allows us to not only take care of the child, but also to equip him for his life going forward.”

Preparing for the future

St. Jude offers a low-vision rehabilitation clinic to enhance the quality of life for children whose sight has been impaired by cancer. Mary Ellen Hoehn, MD, a St. Jude pediatric ophthalmologist, works with occupational therapists to optimize each child’s vision and share strategies that help the patient make the best of the vision that remains. Brayden also received physical therapy and speech therapy at the hospital.

Understanding risks

Retinoblastoma is caused by a genetic defect. There are two forms of the disease: familial, which typically
affects both eyes; and sporadic, which usually involves a single tumor affecting only one eye. Since Brayden has the familial form of the disease, every cell in his body lacks one of its pair of retinoblastoma genes. Although some children inherit this condition, others, like Brayden, develop a new mutation before birth. His big brother, Peyton, does not carry the mutation.

The hospital’s genetic counselor, Christine Odom, helped Drew and Misty understand the mutation as well as the importance of vigilance in monitoring Brayden’s health into adulthood.

“Most people assume that if you have the familial type of retinoblastoma, then one of your family members had to have had the disease,” Odom says. “But that’s not true. Nine times out of 10, it’s a brand new mutation in the child. Brayden’s chance of passing retinoblastoma on to his children, though, is 50 percent with each pregnancy.”

Because he has the hereditary form of the disease, Brayden also is at increased risk of developing second cancers, such as brain, bone, skin or soft-tissue tumors. As he moves toward adulthood, hospital staff will further educate Brayden about how to minimize his risks by adopting good health practices and obtaining regular medical evaluations.

In the driver’s seat

For Brayden, the typical challenges of cancer treatment have been augmented by other problems, including surgery to treat a severe ear infection; several dangerous allergic reactions; a bout of influenza that occurred when he went home for a visit; and numerous issues that arose because of toddler antics.

“When he was inpatient, he would go fishing with his IV pole,” Misty says. Brayden would tug on the tubing attached to the pole, reeling the equipment closer and closer until he could hit the “off” button. He also chewed through his central line, the catheter that had been inserted into his chest for the infusion of medicines. “He was a troublemaker,” his mom says, with a sigh.

Today, it’s hard to believe that the energetic little firecracker with the Technicolor imagination has a visual impairment. Brayden runs, fingerpaints, rides a bike. He wiggles his hips to demonstrate his hula hoop prowess. He identifies colors and proudly counts to 14.

“When Brayden was first diagnosed, I sat in the chair and cried, thinking that my world was over and that my baby was going to have this horrible life that I had dreamed up in my head,” Misty says. “But he has a great life. He loves to go to St. Jude—all the people he gets to meet and all the things he gets to do.

“We’ll never be able to say ‘thanks’ enough to the doctors, nurses and all the other staff who are helping our son,” she says. “We never imagined our child would be a St. Jude kid, but he is, and we are so blessed to have them.”

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Retinoblastoma

This rare tumor can occur in one or both eyes.

It is caused by a genetic defect in the retina, the light-sensitive tissue at the back of the eye.

250-300 children in the U.S. develop retinoblastoma each year.

40% of children with retinoblastoma have tumors in both eyes. These are all caused by the hereditary form, which means the mutation occurs in all of the body's cells.

60% of children with retinoblastoma have disease in only one eye. Of these, most have the sporadic (non-hereditary) form.

95% survival rate for children whose tumors have not spread beyond the eye.

50% risk with each pregnancy that individuals with hereditary form of retinoblastoma will pass the mutated gene to their children.

Children who have retinoblastoma in both eyes generally have the familial form of the disease. Although some children inherit this mutation from their parents, others, like Brayden, develop a new mutation, which can be passed on to future generations.
In the Bone Marrow Transplant unit at St. Jude Children’s Research Hospital, dinosaurs are running amok. A fearsome stegosaurus, an elegant apatosaurus and a bright red plastic triceratops trample palm trees, fight their way across the bed sheets and transform the attitude of a boy named Daniel Rowe Jr. While Daniel’s grandmother relaxes, the 5-year-old and his new friend, “Paw,” engage in some serious fun.

Paw, also known as David Fisher, is one of about 50 specially trained volunteers who give caregivers a break through a program known as Helping Hands. Believed to be the first hospital-based respite care program of its kind for pediatric cancer patients and their siblings, Helping Hands offers families a precious commodity: stress relief.

The process is simple. A caregiver merely asks a hospital staff member to contact Helping Hands. Available seven days a week, the program provides up to two hours of respite service for inpatients, outpatients and their siblings.

“We use the volunteers a lot,” says Daniel’s grandmother, Dannielle Mixon, who alternates caregiving duties with Daniel’s mom, Christine Hardy. “Today, a volunteer came so I could run downstairs to the gift shop and get Daniel a little surprise. We’ve also asked for help so we could just walk outside and get some fresh air. Or do a load of laundry or take a shower or get something to eat.”

**Stress busters**

Cancer treatment is stressful under the best circumstances. For caregivers of children with cancer, this stress may be compounded by the frenetic activity of...
healthy siblings and the unrelenting tedium of sitting in a hospital room for days, weeks or even months. If the treatment occurs far from home, the adult caregiver may not have the luxury of calling upon family members for support.

Although many hospitals offer respite care to families in crisis situations, St. Jude has made it a routine part of clinical care. And while many other hospitals require advance appointments for such services, St. Jude offers it immediately upon request, depending on volunteer availability.

“Our Helping Hands volunteers have set shifts each week, with the sole purpose of doing respite care. That kind of coverage doesn’t occur in most hospitals,” explains Director of Volunteer Services Kathryn Berry Carter, who recently coauthored an article on the program that appeared in the Journal of Pediatric Oncology Nursing. “We also have one staff person dedicated to coordinating the volunteers’ schedules, funneling critical information to them and constantly updating their training.”

Program participants complete an intensive training regimen that includes shadowing a seasoned volunteer. Although assigned to specific focus areas, Helping Hands staff members are trained to respond to families throughout the hospital—whether in inpatient rooms, Intensive Care Unit or outpatient clinics. The program has been wildly successful, with approximately 1,320 interactions last year alone.

Opportunities abound

Helping Hands volunteers offer many reasons for participating in the program.

“It’s fulfilling to give back to St. Jude, because St. Jude gave so much to us.”

David Tuttle, an orthopedic engineer, became intrigued by the hospital when he ran the St. Jude Memphis Marathon several years ago. He had been seeking a volunteer opportunity, and Helping Hands fit the bill.

“Caregivers need to be able to step away without worrying about who will spend time with their children,” says Tuttle, who admits he is just as happy to play a spirited game of Candy Land as he is to sit in a darkened room and watch the gentle rise and fall of a baby’s chest as she slumbers.

Jack Ingram, the dad of two teenagers, says his motivation comes from the patients and families themselves: “I love putting smiles on the kids’ faces,” he says.

Adventures in play

Helping Hands sessions sometimes occur outside the confines of a hospital room. Volunteer Randa Rosenblum understands the value of a change of scenery.

“I’ve found that the more I can get a patient out of his or her room, the better it is,” she says. “I can almost feel them taking a breath, just getting out of those four walls.”

To children at St. Jude, Helping Hands volunteers are synonymous with “play.” Recently, Rosenblum entered a room and met three siblings—ages 4, 5 and 6. While the parent shared a quiet moment in the room with the patient, Rosenblum took the siblings on a rollicking adventure. They climbed on the concrete balls near the garden labyrinth, raced around the Danny Thomas statue and checked out the tropical fish in the hospital’s large aquariums.

Sometimes at night Rosenblum takes children to a glass-enclosed hallway with a view of the city, and they dance to the music of a small radio. Occasionally, she and siblings lie on their backs in the grass and identify animal shapes in the clouds.

“The siblings sometimes are just as much in need of Helping Hands as the patients are,” she explains. “To be able to get outside and explore and be creative and laugh and dance is meaningful for all of us.

“I get far more out of Helping Hands than I could ever imagine,” she continues. “I love being with the kids. It’s pure joy. They’re incredibly strong, courageous, open children, who are full of hope. I’ve been given so much by being with them and their families. It has transformed my life.”
Breathe

St. Jude combines yoga and nutrition in a program designed to complement cancer therapy.

BY CARRIE L. STREHLAU


The teenagers sit motionless in a dimly lit space. The soft murmur of wind chimes hangs in the air as the group collectively takes in a breath, holds it, slowly lets it out. Namaste.

A practice that dates back centuries, yoga is being intertwined with a focus on nutrition for patients at St. Jude Children’s Research Hospital. In late 2011, the Clinical Nutrition and Rehabilitation Services departments partnered to create a wellness program that combines yoga with a healthy eating class for young patients.

Yoga is not new in the health care field, but it is gaining momentum as a formal program within hospital settings.

“We’re focusing on all of the benefits of yoga, which include balance, coordination, a decrease in pain and improving quality of life,” says Jessica Sparrow of St. Jude Rehabilitation Services. An occupational therapist trained in providing yoga for children, Sparrow adds that having this special combination of yoga and nutrition as a service provided for patients is a true complement to treatment.

“Our ultimate goal is that they take this practice into their everyday lives—like breathing exercises to...
help with anxiety and pain,” Sparrow says. “We intend to monitor the outcomes and track the progress as evidence-based research to not only improve upon existing knowledge at St. Jude, but also to share with others.”

Sparrow works with Danielle Doria, also of Rehabilitation Services, and Karen Smith of Clinical Nutrition to create the program’s outline. After each yoga session, patients get a lesson on healthy eating, which often includes a hands-on demonstration from a St. Jude chef.

“We focus on foods that bring them out of their comfort zone but at the same time are tasty and healthy,” Smith says. “The younger kids are more open-minded about trying new foods. The parents, who are present at the sessions, can see that their children are eating hummus or something they might not have thought they would try. It encourages the families to make good food choices.”

Also a licensed occupational therapist, Doria is enrolled in a special certification for yoga therapy, which will eventually allow her to expand the program to treat more medically complex patients.

“We use yoga to meet the child at his or her level of strength, which is what makes this practice so perfect for the children at St. Jude,” Doria says. “We can alter it to fit their needs, giving them a sense of empowerment, which is important when they’re going through treatment.”

The combination program has been successful, with many of the patients using basic poses at home or even in the hospital’s hallways. “We want to offer healthy options like yoga and good nutrition so they can be healthy survivors,” Smith says.

In 2013, the hospital added a class especially for teenaged patients.

Fifteen-year-old Charles Scott, undergoing treatment for the brain tumor pineoblastoma, was thrilled to participate, especially because he had not previously practiced yoga.

“It has helped me to keep from hurting so much,” says Scott, who also practices the poses at home.

“To me, the most rewarding aspect is seeing these kids—who are going through life experiences most people don’t until later in life—gaining physical and emotional strength and changing their eating habits,” Doria observes. “It’s really empowering.”

Vegetable Hummus

St. Jude staff find simple and nutritious recipes to share with patients. Here is one of their favorites, which can be made ahead in less than 10 minutes.

Ingredients
2 cloves garlic
2 cans (15 oz. ea.) chick peas [or garbanzos], rinsed and drained
1 package Knorr® Vegetable recipe mix
½ cup water
½ cup olive oil
2 Tbsp. lemon juice
¼ tsp. ground cumin

Directions
1. Process garlic until finely chopped in food processor. Add remaining ingredients; process until smooth. Chill at least two hours.
2. Stir hummus before serving. If desired, add 1 to 2 tablespoons additional olive oil. Serve with your favorite dippers, such as baby carrots and celery sticks.

Makes 3 ½ cups.

For complete nutrition information, visit www.knorr.com.
Rhodes College students Matthew Cannavo (at left) and Sierra Thompson took a break from their work at Calvo Mackenna Children’s Hospital to ride their bikes through the Chilean countryside.

"My favorite part of the hospital experience was visiting with patients and seeing what the daily experience was like for someone in the medical field there," Thompson says.

In the afternoons, students attended a school for international students to brush up on their Spanish skills. Each student lived with a host family throughout the eight-week period, which allowed for some sightseeing adventures to nearby cities on weekends.

After returning to Memphis, Thompson and Rhodes student Matthew Cannavo, who also spent time in Chile for the program, began working with James Hoffman, PharmD, St. Jude medication outcomes and safety officer, for 10 hours a week. The students focused on tasks related to medication safety and quality.

"St. Jude is a great learning environment for these students interested in careers in health care and science to receive training," Hoffman says. “Their contributions are mutually beneficial.”

The program offers aspiring scientists and clinicians a glimpse of how St. Jude is impacting the world.

“Working in both environments—in Chile and at St. Jude—has been wonderful,” says Thompson, who is interested in practicing medicine abroad. “It’s been a valuable learning experience in many ways.” ●
At the intersection of social media, fundraising and the entertainment industry stands a young girl who has discovered the power of Twitter. Since 2010, 12-year-old Bailey Browning of Virginia has raised nearly $62,000 for St. Jude Children’s Research Hospital with her Twitter account and support from the fans and cast of her favorite TV series, Chuck.

“Since I have a healthy life, I should be able to help the kids who aren’t as fortunate as I am. I’ve seen what St. Jude can do, and they save lives,” says Bailey, who met one of the hospital’s patients, Kaley Shoemaker, when the girls were both in kindergarten and Kaley was undergoing acute lymphoblastic leukemia treatment. Today, Kaley is a healthy middle school student like Bailey.

Because of Kaley, the elementary school became a leading fundraiser in the St. Jude Math-A-Thon® program. When the school allowed students to set up personal fundraising pages, Bailey posted her page’s links on Twitter and set a goal of $250.

“Within an hour she hit that target,” says her mother, Sara Browning. “It was crazy. She kept raising her target and kept meeting it. After three weeks, the final total was over $5,000.”

As an avid Chuck fan, Bailey had a large Twitter following, and those friends helped spread the word.

“If I tell one person about St. Jude and they tell their friends, it just keeps the message going, and social media really helps that,” Bailey says.

At Chuck fan events, Bailey and her mom met cast members, including Zach Levi and Yvonne Strahovski. The Chuck cast has re-tweeted Bailey’s St. Jude messages and has donated items for the giveaways she offers on her Twitter page to fuel fundraising.

“The year Yvonne got Twitter was when everything started taking off, and we started getting into the $10,000 and $20,000 ranges,” Bailey says. “She has so many followers.”

In 2013 alone, Bailey raised $22,718 for the hospital.

“To be able to raise $60,000 for a charity like St. Jude using social media and a fandom just blows my mind,” says Sara, who monitors Bailey’s Twitter account (@littlechuckfan). Strahovski calls Bailey’s efforts inspiring.

“I support Bailey simply because she inspires me,” she says. “For someone so young, she is smart and deeply compassionate. Her efforts in fundraising and general charity are astounding. She is a role model for both her peers and adults, and it is my absolute pleasure to stand by her side in support, especially for what’s becoming the annual St. Jude fundraiser.

“We are truly grateful and thankful to the loyal and ever-supportive Chuck fans for their donations each year,” she continues. “They play a big role in supporting Bailey’s commendable initiatives.”
Genome project sheds light on childhood brain tumors

The St. Jude Children’s Research Hospital – Washington University Pediatric Cancer Genome Project has identified mutations responsible for more than half of a subtype of childhood brain tumor that takes a high toll on patients. Researchers also found evidence the tumors are susceptible to drugs already in development.

The study focused on a family of brain tumors known as low-grade gliomas (LGGs). Nationwide, surgery alone cures only about one-third of patients with this tumor.

Using whole genome sequencing, researchers identified genetic alterations in two genes that occurred almost exclusively in a subtype of LGG called diffuse glioma. Together, the mutations accounted for 53 percent of the diffuse gliomas in this study. The findings appeared in the scientific journal Nature Genetics.

“This subtype of low-grade glioma can be a nasty chronic disease; yet, prior to this study we knew almost nothing about its genetic alterations,” said David Ellison, MD, PhD, Pathology chair, and the study’s corresponding author. The first author is Jinghui Zhang, PhD, Computational Biology.

Eat and destroy

Cells in the immune system have ancient defense systems that allow them to “eat” and destroy pathogens in the body. Now, St. Jude scientists have evidence that a process that allows cells to quickly switch from “eating” mode to “destroying” mode might offer a new approach for taming the misguided immune response at the heart of autoimmune diseases.

The process allowing the switching event, called LC3-associated phagocytosis (LAP), was identified in the laboratory of Douglas Green, PhD, Immunology chair, and first described in research previously published in Nature.

Now researchers have found that LAP may, in some circumstances, trigger inflammation and an inappropriate immune response. The latest findings were published recently in the journal Immunity.

The study showed LAP is involved in the cell signaling that unleashes production of type 1 interferons. These proteins help defend against viral infections; the proteins have also been linked to autoimmune diseases like system lupus erythematosus, which strikes children and adults. Such disorders occur when the immune system attacks healthy tissue.

“The finding raises the possibility that lupus patients might benefit from treatments that target the machinery of LAP,” Green said.
Bird flu: A new tool in the arsenal

Hassan Zaraket, PhD (at left), and Charles Russell, PhD, of St. Jude Infectious Diseases recently led research that identified a new indicator to determine the risk that avian H5N1 influenza viruses pose to humans. The research could lead to improved influenza surveillance, more efficient vaccine production and new tools to ease the risk of a pandemic.

The H5N1 influenza virus—otherwise known as the “bird flu”—has sickened at least 620 people since 2000 and is responsible for at least 367 deaths. However, its global reach has been limited by the fact that the virus cannot spread efficiently from one person to another. Health officials fear that if the virus acquires that capability, it would lead to a pandemic and public health emergency.

“Our ultimate goal is to understand what makes one influenza virus grow and spread in birds versus another that is able to grow and spread in mammals,” Russell said. “Knowing the answer could aid efforts to identify and track high-risk H5N1 avian influenza viruses and better prepare for a possible pandemic.”

Survivors and renal cancer risk

Childhood cancer survivors are at increased risk of developing renal cancer as young adults. Preliminary evidence from a St. Jude-led study points to several factors that may be connected to this increased risk, including kidney irradiation and treatment with platinum-based chemotherapy drugs.

Even though renal cancer is typically a disease of older age, research published in the *Journal of the National Cancer Institute* found unexpectedly high rates of the tumor among adult survivors who were treated for childhood cancers when they were less than 20 years old. The survivors were participants in the Childhood Cancer Survivor Study (CCSS), a multi-institutional cohort study led by St. Jude. The survivors had renal cancer at eight times the rate expected in the general population.

Carmen Wilson, PhD, and Greg Armstrong, MD, both of St. Jude Epidemiology and Cancer Control, led the research. They found evidence that survivors whose pediatric cancer treatment included cisplatin or kidney irradiation of 5 gray or more faced a nearly fourfold higher risk of being diagnosed with renal cancer later.

Survivors’ Day 2013

Hundreds of St. Jude survivors will return to St. Jude for the 15th annual Survivors’ Day Conference, September 6–7. The keynote speaker is actor, author and cancer survivor Hill Harper (pictured above). The event will also feature a panel of childhood cancer survivors. Join the live webcast; details are available at stjude.org/survivors-2013.
Beam of hope

About 300 employees from St. Jude, Children's GMP, LLC, and ALSAC recently wrote inspirational messages to patients and families on beams that will become a permanent part of a new clinical and research building being erected on campus. With construction on the project taking place just yards away, employees penned well wishes, thoughts and prayers on the beams. The signing was intended to be a permanent gift of love for patients and their families, surrounding them with wishes for good health and happiness incorporated into the building.

“Rheostat” helps T cells match response to threat

A properly functioning immune system is a lesson in balance, providing protection against disease without attacking healthy tissue. Work led by St. Jude scientists and published recently in *Nature Immunology* has identified a mechanism that helps components of the immune system called T cells find that sweet spot where the strength of the immune response matches the threat.

T cells use a variety of weapons to combat cancer and viral infections. “T cells are a double-edged sword, capable of launching a fierce attack to defeat an infection but also wreaking havoc if the response is too robust and results in damaging healthy tissue,” explained the paper’s senior author, Dario Vignali, PhD, Immunology vice chair.

Receptors embedded in the T cell membrane serve as a communication channel that enables the T cell to match its response to the threat. The researchers found that part of the T cell receptor functions like a rheostat, helping to regulate the sometimes explosive production of new T cells called proliferation.

The finding offers important insight into the immune response. The work also lays the foundation for advancing our understanding and treatment of problems that arise when the system malfunctions. For example, autoimmune disorders can occur when the immune system mistakenly targets healthy tissue, whereas an insufficient immune response can lead to chronic infectious diseases or cancer.

“These findings suggest how T cell receptors help to manage the response and possibly guard against complications resulting from an overly aggressive response,” Vignali said.

Dyer named HHMI investigator

Michael Dyer, PhD, of St. Jude Developmental Neurobiology, is one of 27 scientists nationwide to be selected this year as a Howard Hughes Medical Institute (HHMI) investigator. The third HHMI investigator currently working at St. Jude, Dyer is an expert in the fields of developmental neurobiology, cell cycle regulation, stem cell biology, developmental therapeutics and cancer genetics.

“Being selected as an HHMI investigator is a great honor for any scientist, and the additional funding it provides will accelerate Dr. Dyer’s research and the impact he is having on the treatment of childhood cancers,” said Dr. William E. Evans, St. Jude director and CEO.
A man of few words and strong principles, Vince Licare still works full-time—with no immediate plans to retire—at the company he founded more than 40 years ago. The octogenarian is deeply committed to his family, and next to their photos on his office desk are pictures of kids at St. Jude Children’s Research Hospital.

“St. Jude has always been something Vince feels strongly about,” explains Liz, his wife of 24 years, who works in the business with him. “He sees the work they do and thinks it’s very worthwhile.”

Vince’s business is Midwest Diesel Service, a dealer in Detroit Diesel engine parts that provides service throughout southeast Missouri, including equipment for river and quarry work.

Giving to St. Jude is Vince’s way of sharing his good fortune. “I’ve been blessed and had a good family,” he says.

After giving generously to St. Jude for more than a decade, he donated highly appreciated stock to establish St. Jude charitable gift annuities for several of his siblings and their spouses. A charitable gift annuity provides payments for life, with a portion of the gift going to help the children of St. Jude. As the oldest brother, Vince has always looked out for his brothers and sisters, and he saw a great opportunity to help them and the children of St. Jude at the same time.

“He has a big heart and just wants to do what he feels is right,” says John Householter, the Licares’ senior philanthropic adviser at ALSAC, the organization that raises funds and awareness for St. Jude.

Vince grew up “on the hill”—an Italian neighborhood in St. Louis, Missouri. His father was a meat cutter and his mother helped in the family store and raised their nine children.

Vince enlisted in the Navy during World War II and was stationed on a minesweeper, where he learned about diesel engines. After the war, he went to work for a Detroit Diesel franchise in St. Louis; after several promotions, Vince decided he could “do it better.” In 1968, he went out on his own.

Liz, a Kentucky native, has three children, and Vince has one surviving son, all from previous marriages. The couple is thrilled to have six grandchildren living near the 120-acre farm that is their home.

The Licares hope to make a trip to Memphis to tour the hospital sometime soon.

“Vince and I have a running joke that as soon as I show up to run his business for a few days, he’ll be able to take time off and visit St. Jude,” Householter says. Although wary of holding up his end of the bargain, Householter looks forward to showing the Licares the impact their generosity is having on the children of St. Jude.

By setting up charitable gift annuities, Vince Licare and his wife, Liz, are helping both their family and St. Jude. To learn more about St. Jude charitable gift annuities, call (800) 395-1087.
In 1981, our 7-year-old son was diagnosed with Hodgkin lymphoma, and we were referred to St. Jude Children’s Research Hospital. This was, at the time, the scariest experience we had ever faced. Todd underwent surgery to determine whether his cancer had spread and to stage his Hodgkin so that an appropriate treatment could be delivered. His protocol consisted of radiation to the upper part of his body. We’ve never seen a medical staff as dedicated and caring as that team of doctors, radiation staff, lab staff and others. We truly believe St. Jude saved Todd’s life when he was a child. When he turned 18, his scheduled appointments stopped.

But the story doesn’t stop here.

In September 2012, a large tumor was discovered on Todd’s thyroid gland. We contacted the operator at St. Jude to explain the situation. She immediately put me in touch with Dr. Melissa Hudson, director of the hospital’s Cancer Survivorship Division.

Dr. Hudson was as interested and caring as our doctors had been in 1981. We couldn’t believe they still cared—this was 31 years later! Not only did Dr. Hudson explain that this was probably a result of childhood radiation, but she called us several times during the next weeks to check on Todd’s surgical results and progress. The tumor was not malignant, but the entire thyroid gland had to be removed and thyroid replacement therapy had to be started. We were thankful again for St. Jude doctors being there for us.

But the story goes on.

After that surgery, Todd visited St. Jude to undergo the follow-up tests that the St. Jude LIFE clinical team does for long-term survivors. During this three-day series of tests, an area of concern was found on Todd’s right side. A renal ultrasound revealed a mass in his right kidney. This time, the tumor was malignant.

The St. Jude physician personally contacted Todd’s local doctor with test results and recommendations. Surgery was performed in December of 2012 to remove the tumor.

Todd’s local surgeon said this tumor had probably been there for two or three years, and if it had gone much longer it could have been life threatening. So, St. Jude again saved our son’s life at age 38.

Everyone who hears this story is in awe of the dedication St. Jude has for the overall health and well-being of childhood cancer patients, even into their adult years. We think God truly had his hand in the establishment of St. Jude, and as parents of a now 39-year-old patient, we are eternally grateful.
The very fact that you are holding this magazine is proof that you care. In fact, it is because of you that kids like Gissel will have a fighting chance to experience the beautiful moments of their lives. Yes, because of you. Your legacy gift is a powerhouse in terms of research and care. It will allow researchers and doctors to continue to peel away the layers of pediatric cancer and other deadly childhood illnesses. Let this be your legacy; that one day no child will die in the dawn of life. Join St. Jude in finding cures and saving children.

Begin your legacy today. Call 800-910-3188 or visit stjudelegacy.org.
St. Jude Formal

By St. Jude patient Austin Otey

From day one to graduation, high school is a time of both joy and pain, where young adulthood is plagued by drama and emotion. There is no good time to receive a cancer diagnosis, but I must admit missing out on senior year has had more than its own share of grievances. All the things that made the first three years of high school bearable have been taken from me and have instead been replaced by drama and emotion of a new breed.

As wonderful as St. Jude is, it can never truly give back what I and my peers here have lost. But by the same token, St. Jude has found a way to provide us with at least a substitute. The St. Jude prom gives us the chance to both feel like regular teenagers again and to celebrate our battle here. The prom shows every kid here that even in the face of all this pain, there is something to celebrate.