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## After Leukemia, Family Struggles to Define 'Normal'

**Jack Streeter, 8, Joins Ranks Of Cancer Survivors Coping After Treatment**

### The Challenge of Kickball

By **AMY DOCKSER MARCUS**  
 Staff Reporter of **THE WALL STREET JOURNAL**  
 June 9, 2004; Page A1

NATICK, Mass. -- This month, Jack Streeter will finish the second grade, his first full year at school since being diagnosed with leukemia. By any measure, it will be a celebratory moment.

Two years ago, his parents thought he was going to die. Now the 8-year-old boy is back at school, and thriving. He sits in the top reading group in his class. He just earned a purple belt in karate and hit a single at a recent baseball game. This summer, he plans to go to camp.

Still, this year has been anything but ordinary for the family. After years of focusing on saving Jack's life, they are now facing a new challenge: trying to get back to normal.

"There are so many things we have to worry about for the rest of his life," says Jack's mother, Debby. "But how can I say that without sounding ungrateful, when I am so happy he is alive?"

Reminders are frequent that Jack's treatment will continue to cause him health problems. In the past two years, he had 13 cavities filled and two teeth pulled. His years of chemotherapy and radiation put him at increased risk for a range of dental problems. He underwent two surgeries to remove cataracts in his eyes, another side effect of the drugs. His mother insists he wear sunscreen whenever he's outside because the full-body radiation makes him more susceptible to melanoma. He is tested regularly for potential cognitive and learning issues.



**Jack Streeter**

There have been less-anticipated problems too. Mrs. Streeter, 43, who stopped working two years ago to take care of Jack full time, says she feels adrift now, unsure whether he is well enough for her to return to work. For her husband, Larry, 48, Jack's recovery is bringing back uncomfortable echoes of an ordeal in his own life. The couple say they find it difficult to engage in small talk with other parents in this affluent suburb, 25 miles from Boston. Their relationship with many neighbors, people who rallied around the family after Jack got sick, has become strained now that he is better.

"For many people," says Scott Armstrong, Jack's oncologist at the Dana-Farber Cancer Institute in Boston, "one of the most stressful parts of cancer comes when the treatment stops."

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**Jack Streeter**

For decades, cancer treatment has focused on trying to save a person's life, not on how it was lived afterward. But in recent years, new therapies have helped increase the number of people surviving five years or more after diagnosis. With this growing success has come the recognition that cancer survivors have special physical and emotional needs. Many will finish treatment and go back to their old lives, only to find that their lives aren't the same.

The President's Cancer Panel, an advisory board established by Congress, released a report on Friday calling for more services to deal with problems people face after treatment is over. The report concludes that some survivors suffer depression and other psychological issues for years.

"We have always focused on how patients physically survive the toxicity of treatment," says Mary Morris, survivorship-research coordinator at the University of Nebraska Medical Center in Omaha, one of several hospitals that have launched studies tracking the long-term health, social and emotional issues of cancer survivors. "But we need to learn more about how they emotionally survive and get on with their lives." Children with cancer pose special challenges of survival, since their experience also transforms the lives of their parents, and often their wider community.

Jack was diagnosed with cancer when he was just 3 years old. His mother noticed he was unusually fatigued, and while giving him a bath, saw bruises all over his body. He spent the next two years undergoing chemotherapy. He seemed to respond, and doctors were optimistic he would be among the 80% of children who are disease-free after two years of treatment.

But in 2001, just a few weeks after starting kindergarten, Jack relapsed. When doctors told his father the leukemia had returned, "I feared this was it," Mr. Streeter recalls. His best option, doctors said, was a bone-marrow transplant.

After the transplant, Jack stayed home for eight months, because he had no resistance to disease. He had a tutor until he got stronger. When he was finally well enough to go back to school in April 2003, his parents were overjoyed -- and conflicted.

**PRESIDENT'S CANCER PANEL**

Read the President's Cancer Panel 2003-2004 Annual Report: "[Living Beyond Cancer: Finding a New Balance.](#)" (Adobe Acrobat is required).

"We can't begin to tell everyone how long we've waited for this day!" Mr. Streeter wrote in an online journal entry. "On the one hand, we were so happy to see Jack return to school with his friends," he wrote. But they were also nervous, he said, knowing Jack's exposure to bacteria and viruses was going to increase.

**Following Rules**

This year, Nell Getz, Jack's second-grade teacher at Natick Memorial Elementary School, says she has focused on getting him used to following rules. Some things he needed to learn are common issues for children who haven't spent much time in a classroom. When Jack knew the answer to a question, he shouted it out without raising his hand. He had a hard time standing quietly in line.

In order to support Jack's transition back to school, four children from his neighborhood were placed in class with him. Mrs. Getz says his two closest friends were always trying to take care of him, bringing him paper or books. She put a stop to that, insisting Jack fend for himself. "More than the other children here, Jack doesn't want to be different," she says. "He doesn't want to be the sick kid anymore."

Earlier in the year, Mrs. Getz tried to get Jack to talk about his cancer experiences in class but he repeatedly refused, she says. She stopped asking. When she asked the children to write about something they did that was courageous, Jack wrote about breaking a board with his hands at karate class. One morning, in a group discussion, a girl mentioned Jack had been in the hospital. Mrs. Getz asked him if he wanted to say something about that. Jack declined, she says, looking down at his sneakers.

Where Jack struggles in school is mainly at recess, Mrs. Getz says, when his closest friends go off to play kickball. Self-conscious about being less athletic, Jack, who has close-cropped blond hair and glasses, stands on the sidelines. When he first returned to school, he didn't know the rules of baseball, basketball or other games the kids played in gym. He had spent a lot of time in bed and playing video games. His face was puffy from the steroids he took, and

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Performance-chasing is a losing strategy



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he had very little stamina.



Jesse Nemerofsky/Mercury Pictures  
The Streeter family: Jack, Larry, Annika and Debby

A few months ago, one of his friends was reaching to pick up a mitten that fell on the floor and elbowed Jack in the stomach as he got up. Jack hit the boy in the jaw, knocking him to the ground, and got sent to the principal's office.

Jack still won't talk about the incident. His mother thinks it came out of his growing frustration at always being the smallest, at having to try so hard to keep up physically with his friends. "When he first went back to school, he got a pass," says Mrs. Streeter. "He was the kid who had cancer. Now, he's treated like everyone else. I think he was tired of people pushing him."

For Mr. Streeter, Jack's struggles remind him of his own. Twenty years ago, at the age of 28, doctors found a large mass in Mr. Streeter's chest. At first, they thought it was benign. But during surgery, after they broke his ribs to get to it, they saw it had grown close to his heart and couldn't be removed. More tests indicated it was malignant, and the cancer had spread to lymph nodes in his abdomen. Mr. Streeter, who was married to his first wife and had a 1-year-old child at the time, underwent a year of treatment, including chemotherapy and radiation. He lost all his hair and, at 5-feet-8, dropped to 106 pounds.

He pushed himself to go back to his job as an information-technology specialist as soon as he could. Friends would stop by his desk, he says, tell him he looked terrible, and wonder why he wasn't home resting. Instead, he started working out everyday. "I wanted to prove to everyone that I was healthy, that I had beaten it," says Mr. Streeter, who keeps in shape by training for an annual 160-mile bike ride to raise money for cancer research.

Mr. Streeter says he and his first wife grew apart. Two years after being diagnosed with cancer, he moved out of the house. The couple, who had two children together, later divorced.

He knew Debby from work and they started dating. They married, and had Jack and his younger sister, Annika, now 5. "I have been reliving everything since Jack got diagnosed," Mr. Streeter says. "Not just the being sick part, but also the difficulties in going back to your regular life."

### New Focus

In April, Mrs. Streeter was in the gym at Jack's school, which was holding its annual "jumpathon" for charity. The gym was packed with children and parents watching third- and fourth-graders jumping rope. Music blared, children shouted. The students were raising funds for the American Heart Association.

For the previous two years, the event raised money for cancer research. The first year it was called "Jump for Jack," and children wore T-shirts with Jack's name on them. Last year, when Jack was able to attend class for the final months of first grade, they called it the "Jack is Back" jumpathon. The children raised a total of more than \$30,000 in those two years.

Todd Kiley, the physical-education instructor who spearheaded the drive, says now that Jack is at school full time, he thought it was time to focus on another cause. Next year, Jack will be jumping rope with others in the third grade. "I didn't want to put that kind of pressure on him," says Mr. Kiley, "having him jump rope for something associated with himself. I don't want to single him out."

Mrs. Streeter looked around at the gym, decorated with banners. Jack's name was nowhere to be found. "It's strange to be here just as another parent coming to a school event," she says. "Strange but good." Yet this year, when children knocked on her door asking for a pledge, she says she was reminded how hard it is to put everything behind them. Confused, the children forgot the name of the charity and said they were collecting money for "jumping for Jack."

It hasn't been easy for the Streeters' neighbors to move on either. In many ways, Jack's health dominated the life of the neighborhood for years, and the family acknowledges an outpouring of support. But now that Jack's treatment is over, "our relationship with the Streeters is not the same as it once was," says Rick Savoia, one of the neighbors.

"We miss the closeness."

When Jack was diagnosed in 1999, Mr. Savoia's wife, Tina, was the first person Mrs. Streeter called. Mrs. Savoia later organized the neighbors so that someone cooked food for the Streeters every night. The couple frequently babysat Annika so the Streeters could stay with Jack in the hospital.

One day, after visiting Jack, Mr. Savoia says it hit him that it could have been his son, Nick -- who is one of Jack's friends -- lying in that hospital bed. Mr. Savoia, who had never been a runner, started training for the Boston Marathon as part of a Dana-Farber program to raise money for cancer research. Mr. Savoia has raised more than \$13,000 every year for the past four years running the Marathon in honor of Jack.

Mr. Savoia's eyes welled up as he described how, every year before the Marathon started, he wrote the words, "For Jack," on the front of his shirt. Whenever Mr. Savoia started to falter and wasn't sure he would finish, he says there was always someone on the sidelines that called out, "Keep going for Jack!" That still inspires him, he says.

In February, Mr. Savoia and Mr. Streeter went out for beer. Mr. Savoia says he confronted Mr. Streeter, asking him why he stands apart when the families watch their kids playing baseball, and why he no longer goes to as many neighborhood functions. For both men, the conversation was the first time they'd talked openly about what had been simmering beneath the surface. It also revealed how the end of Jack's treatment has widened, not closed, the gap between their lives.

Mr. Streeter told his friend that he finds it tough to join in the light-hearted banter of his neighbors. It's hard for others to appreciate that Jack's immunizations were totally wiped out by chemotherapy and he remains more vulnerable to infection than other children. He also articulated aloud for the first time his deepest fear: that even now, more than two years after Jack's bone-marrow transplant, Jack might die from his disease -- that he could relapse or get another cancer. Mr. Savoia says his feelings were hurt, though, when Mr. Streeter added, "You don't get it."

"Maybe we don't get it totally because it's not happening to our child," Mr. Savoia said in a later interview. "But we've tried as hard as we can to get it. If we slip up sometimes, if we make a mistake or miss something, I think it should be forgiven." He says he knows the Streeters are still struggling with how to return to normal life. He wants that life to include his family but concedes he isn't sure it will. "I don't know what their definition of normal is anymore," he says.

Mr. and Mrs. Streeter say they aren't sure either. In March, the couple spent a weekend at a retreat sponsored by a camp for children with chronic or life-threatening illnesses. As they sat in a room with 20 other couples who had shared similar experiences, Mr. Streeter said, "This is where I feel I belong." At one point, a priest spoke to the group, telling them it's their responsibility to learn how to live in a world of smaller hurts and more easily corrected grievances. "We've expected others to understand our world and they can't," Mr. Streeter says. "But can we go back to their lives? I don't think it's possible."

Jack's health will need to be closely monitored for the rest of his life. Mrs. Streeter says she recently looked up the medications that Jack used to take on a Web site run by the Children's Oncology Group, a consortium of hospitals that treat pediatric cancer patients. One of his chemotherapy drugs, methotrexate, puts him at a higher risk for learning and memory problems, according to the group. It said Ifosfamide, which Jack received after his relapse, increases his risk of getting a second cancer.

For children who have had the kind of radiation treatment that Jack had, there is a 95% or higher chance that they will be sterile, according to Charles Sklar, director of long-term follow-up at Memorial Sloan-Kettering Cancer Center in New York. Radiation to the brain, which Jack underwent twice, can also stunt growth. Worried because Jack is physically smaller than his peers, his parents recently took him to an endocrinologist to discuss the possibility of taking growth hormones.

At Memorial Sloan-Kettering, child-cancer survivors are tested for cognitive problems every year to two years, even through college. Jack gets similar exams on a regular basis. "Problems can emerge for the first time 10 to 15 years down the line," says Dr. Sklar. "Radiation involves a progressive insult to the brain."

Now that Jack has passed the two-year mark since his bone-marrow transplant, the danger of relapse is receding,

says Dr. Armstrong, his oncologist. But then, the doctor leaned over and knocked on a wood panel on the wall. After Jack completed the standard treatment of two years of chemotherapy, his parents threw a big party to celebrate in June 2001. Dr. Armstrong attended. At the time, it seemed Jack had responded successfully to the treatment.

When Jack relapsed a few months later, Dr. Armstrong was devastated. "I will never go to another patient's party again," he says.

Jack's unwillingness to talk about his experiences is another source of worry for his parents. According to the President's Cancer Panel report, 20% of childhood-cancer survivors experience posttraumatic stress disorder, sometimes years after treatment ends. On the advice of a social worker at Dana-Farber, Mrs. Streeter started keeping a scrapbook of Jack's cancer journey. Someday, she believes, he may want to discuss what happened to him.

For now, Jack prefers to put cancer behind him. On a recent morning, he was playing in the backyard with his sister. Dressed in his uniform for baseball practice, he spread a deck of trading cards on the table on the porch. "I wasn't into sports at first," Jack said. "Now I want to do what my friends do."

He said his friends don't ask him anymore about what it was like to have cancer. "I don't really like to talk about it," Jack said. "We like to talk about sports." When asked what he missed most when he was sick and couldn't go to school, he looked up from the cards for the first time. "Everything," he said. "I missed everything."

Mrs. Streeter says that, in some ways, Jack has been more successful than his parents in finding his way back to the routines and rituals of everyday life. "For me, I never feel I belong in the same world as my neighbors," she says.

Annika needed to get ready for a birthday party and couldn't find her friend's present. She wanted her hair to be brushed and braided. Jack asked to hit some baseballs before practice started. He debated whether he should wear cleats instead of his sneakers. "People are scared about what happened to us, what happened to Jack," said Mrs. Streeter, as she listened to her children's chatter. "They want us to go back to normal quickly because the sooner we do, they can put away their fears and go back to normal too."

She's realized that surviving cancer involves more than physical recovery, she said. "I keep waiting to go back to the way things were," Mrs. Streeter said. "But then I think: What if that doesn't happen? What if this is normal?"

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