

A Real SUPERHERO

By Sue Spiry

FROM THE TENDER AGE OF FOUR, JR WILLIS HAS BEEN BATTLING LEUKEMIA AND ITS RELATED CONDITIONS.

He's undergone months of chemotherapy, a life-threatening fungal infection, three back fractures, a seizure, and numerous broken bones. He's been confined to a hospital bed, a wheelchair, and full body casts.

After almost two years in remission, JR's battle continues today at Baystate Children's Hospital. But despite it all, JR is a happy-go-lucky nine-year-old with a ready smile, a sly sense of humor, and a loving family who considers him a real hero.

FIRST CAME ADAM

When Adam Willis was diagnosed with leukemia at age two, his mother Alice fell apart. "I couldn't stop crying," she remembers. But she and her husband Brian, along with their older son Derek, pulled together to support each other through Adam's three years of treatment at Baystate Children's Hospital. And it paid off. Today, Adam is a 22-year-old college graduate living in Germany with plans to marry in August.

But the Willis family was forever changed by their experience. "You become a different person," says

Alice. She completed the necessary training and the family opened their home to children needing specialized foster care. To date, they have fostered over 100 children, both short term and long.

ENTER JR

The Willis' were fostering a young boy named Rafael when Alice learned about JR. He was receiving treatment in Boston for the same type of leukemia their son Adam had years ago. JR was four years old and basically alone in the world. Believing everything happens for a reason, Alice felt she went through her son Adam's illness so she would be able to help JR.

"The first time I met JR," says Alice, "he looked up at me and asked, 'Are you my new mommy?'" Alice knew right away that she and her family could help JR. "I left in tears because he didn't believe I'd ever come back." But she did, and began the process to bring JR to their home.

BEATING THE ODDS

In addition to leukemia, JR developed a life-threatening fungal infection that invaded his body, attacked major organs and blood vessels, and led to internal bleeding and the removal of his gallbladder. He was in the intensive care unit in Boston for three months while receiving anti-

fungal medications intravenously. Between the infection and chemotherapy, JR also developed osteopenia, resulting in his bones becoming very brittle. From a period between October and June, he suffered three back fractures, a broken left femur twice, and a broken right femur, ankle, foot bone, and elbow. He had to wear a full body cast several times for up to six weeks.

"It was a catch-22," says Alice. "He needed to move to strengthen his bones and muscles, but moving made fractures more likely. The doctors and physical therapists



When he was adopted, JR got to choose his middle name. He chose Spiderman, his most beloved superhero.

weren't sure he would ever walk on his own."

Alice helped JR with his therapy and their perseverance paid off. He graduated from a wheelchair to a tricycle, then from a walker to leg braces. He was almost seven when he was first able to walk on his own.

According to Alice, JR had three goals. The first was to be able to walk. The second was to run. And the third was to win a trophy. He has since achieved all three, having won a trophy as part of his bowling team. Best of all, he could attend school.

ROUND TWO

After almost two years of remission, Alice and Brian noticed some disturbing changes in JR. Now in second grade, he complained of fatigue and had a low grade fever, black and blue marks, and three nosebleeds, all within one week. Alice called JR's oncologist in Boston, who confirmed their fears: the leukemia was back.

Alice says that while about 90% of kids treated for this form of leukemia go into remission and stay there, it wasn't a total surprise when JR fell into the other 10% because he had been too small and weak to withstand the entire treatment protocol.

Alice requested that JR's care be transferred to Baystate Children's Hospital, closer to their home and where she felt most comfortable. "I knew Baystate was a great hospital from our experiences with Adam," says Alice. "Plus it was an easier drive and I knew that their cancer program could provide for all of JR's needs."

A SUPERHERO EMERGES

When Alice and Brian learned another family was considering adopting JR, they had a serious decision to make. When they had begun fostering children, they had no intention of adopting. "We were just a step in their journey," says Alice. But JR was different. "I felt no one else could care for him like we did."

The Willis family began the process to adopt JR and his foster brother, Rafael, who had also become a true part of the family. Brian and Alice told both boys that they could choose their own legal first and middle names, as long as they took Willis as their last name.

JR decided to keep his nickname as his real first name. But for his middle name, he chose Spiderman, his most beloved superhero.

It's a name Alice thinks is perfect for JR. "Kids with cancer are so real," she says. "They put your life into perspective. They live in the now. They are superheroes."

BAYSTATE CHILDREN'S HOSPITAL: A SECOND HOME

"I love Baystate Children's Hospital," says Alice. "It's my hospital. It's where I feel comfortable. It's like a second home."

JR agrees. "They have a cool place to play," he says, referring to the Children's Miracle Playdeck (an indoor/outdoor playscape). "And I get to ride a bike." The first thing he asks for when he arrives? "A warm blanket!" he says laughing while his mom notes how much he loves the blankets from the



"Kids with cancer are so real. They put your life into perspective. They are superheroes."



THE WILLIS FAMILY
Back: Brian and Adam
Middle: Derek, Rafael, and Alice
Front: JR and his hero, Spiderman

blanket warmer on the unit. "He's pretty spoiled there," she says.

When JR is not staying on the children's inpatient unit, he and his parents make regular visits to the

"I love Baystate Children's Hospital. It's like a second home."

Baystate Regional Cancer Program's Sadowsky Center for Children, located within the D'Amour Center for Cancer Care. There, they see pediatric hematologist/oncologists Drs. Satkiran Grewal, Matt Richardson, and Joanna Luty.

Alice describes the care her family receives as "awesome." She points to amenities like valet parking that she says may seem small, but that mean a lot when you have a child

with cancer. "They have everything we need," she says. "They are our extended family. I know JR gets the same level of care he would get in Boston or New York City."

What Alice says she most appreciates is the Baystate team's willingness to listen to what she has to say. "My opinion counts," she says. "They are willing to explore possibilities and research options. When JR is at Baystate, I know he's well taken care of."

HOPING FOR A HAPPY ENDING

JR is now enrolled in a clinical study at Baystate Children's Hospital and undergoing chemotherapy. This time, he is tolerating it well.

JR himself says things are better this time around, but not because

of the treatment. "I have a family now," he says. He also has a list of new goals he'd like to achieve. He'd like to be home for his 10th birthday on June 5. He'd like to be able to travel to Germany in August for his older brother Adam's wedding. And he'd like to rejoin his classmates in September.

Alice sums it up, quoting the sign hanging in her kitchen, which reads, "Live well. Laugh often. Love much." If you do that, she says, "Everything else will work out."

Learn more about pediatric cancer care at Baystate Children's Hospital at baystatehealth.org/bch.

For a referral to a pediatrician on staff at Baystate Children's Hospital, call 1-800-377-4325.