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LOCAL

Jimmy's fight

Jimmy wants to be normal. He wants to hang out with his friends. He wants people to see past his wheelchair. And he wants people to see anything but c

By Robert Gold

THE NEWS-TIMES

The boy won't give up.

He wouldn't stop playing baseball even when the tumor made him throw up before games. He wouldn't quit smiling even when illness stole his voice. He wouldn't give up his dream of running again even as he rode in a wheelchair.

Now, on a winter night in 2003, Jimmy Zarifis stood in the moonlight on the quarter-mile track at Newtown High School and tried to take the next steps in his battle against cancer.

Skinny and still weak from his operation, the 12-year-old boy willed his legs to be strong again.

As always, his family was there for him.

Little brother Steven stood ready to catch Jimmy if he fell. Little sister Michelle cheered him on. Mom and Dad — Elizabeth and Jim — looked on, hoping and praying.

The steps came slowly, painfully. But they came.



The News-Times/Chris Ware



The News-Times/Chris Ware

From right, Jim and his son Jimmy Zarifis, from Newtown, share a moment at a family baseball game in their hometown. Jimmy, who was diagnosed with a cancerous brain tumor, is overcoming the effects of chemotherapy and radiation. The treatments caused osteonecrosis in his hip, which has left him temporarily in a wheelchair.

Ten feet.

Twenty feet.

Twenty-five feet.

Finally, 30 feet.

Jimmy's family rushed to hug him.

"What an awesome thing to have us all work like this," his father thought.

For the past two months, thousands of people from Danbury, Newtown, Ridgefield, New Milford and other towns have taken part in events called the Relay for Life. Much has been said and written about how much money the events raise and how they serve as a celebration for cancer survivors.

But the events don't begin to hint at the long, rough road the survivors have traveled. To truly understand what it takes to fight the

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Jim Zarifis looks over his son during an acupuncture treatment.

disease, just walk a mile in the shoes of someone like Jimmy.

Nearly two years after that night at the Newtown track, it would be nice to say Jimmy's recovery is complete. It would be nice to say the love of his family, the labor of doctors and therapists and the boy's own courage and character had carried the day.

But it would not be true.

Awesome moments still share time with awful ones. Steps forward mix with setbacks. Jimmy has moved a little farther around the track, but his health hasn't come full circle.

Still, the boy won't give up.

A mystery illness

Jimmy Zarifis was never a big kid. But he had always been healthy, strong, energetic. Played basketball with friends. Kicked around a soccer ball with Michelle.

But baseball was his first love.

He picked up his first bat when he was a toddler. By age 5, he was in youth leagues. Mostly he played shortstop like his idol, the Yankees' Derek Jeter.

And he was good.

"They would say, 'Hit a home run, Jimmy,' so I'd hit a home run. "They would say 'Hit a double, Jimmy,' so I would hit a double. They were just joking but I'd do it."



The News-Times/Chris Ware
Jim Zarifis helps his son Jimmy with his wheelchair at Treadwell Pool in Newtown last summer.

nearby woods, vomit between the trees and sprint back onto the field, ready to play.

Jim and Elizabeth Zarifis started to worry. Could it be a food allergy? Jim scoured the Internet for clues. Was his son allergic to wheat? Corn products?

In June, Jimmy had an endoscopy — a tiny fiber optic camera was inserted in the body. It revealed nothing.

In August, Jimmy contracted Lyme disease. Doctors thought maybe the tick-borne disease was the root of his problems. His father doubted it. Most people with Lyme disease don't lose 20 percent of their body weight.

At 4-foot-8, a healthy Jimmy had barely tipped the scale at 75 pounds. "He did not have an ounce of fat on him," his father said. Now Jimmy was down to 62 pounds.

Doctor ordered a CT scan. On Sept. 28,



The News-Times/Chris Ware
Jimmy and his mother, Elizabeth, visit the Praxair center at Danbury Hospital. The cancer treatments have caused Jimmy's immune system to become unstable. Elizabeth and Jimmy made regular visits to Praxair for blood work tests.

In April 2002, Jimmy was 11 and getting ready for a new season in Newtown. So was his 8-year-old brother, Steven.

First, they had to get over a stomach virus. The boys and Michelle, then 5, spent two days throwing up and generally feeling lousy. Soon, Steven and Michelle got better. But not Jimmy.

Baseball season started, and he fell into a unnerving routine. Not wanting to throw up in front of his teammates, he would run to the



The News-Times/Chris Ware
Jimmy watches his brother's baseball game. Brain

Bethel



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2002, Jimmy and his parents headed to Danbury Hospital. They hoped the images of Jimmy's stomach might help solve the mystery.

surgery left Jimmy unable to play the game he loves.



The News-Times/Chris Ware

Jimmy copes with stress prior to taking the scholastic Connecticut Mastery Test while at school in Newtown.

They had the wrong body part.

A radiologist walked up to Jim. His words seemed meant for someone else: Jimmy had a brain tumor.

"I need to tell him my name," Jim Zarifis thought. "He can't possibly be talking about Jimmy. He has the wrong dad."

The golf-ball-sized tumor was a medulloblastoma, a cancer usually found in children. Later, Jim and Elizabeth would learn that 80 percent of the kids with this cancer live at least five years. But at this moment, all they could think is: "My son could die."

Jim Zarifis and his oldest son always had a deep connection. Moments after his birth in a Bronxville, N.Y., hospital, Jimmy seemed to recognize his father's voice, turning toward it again and again. The newborn spent his first night sleeping on his dad's

chest.

As Jimmy grew up, he would help his father work on computer equipment. He would crawl underneath desks and hook up wires. On New Year's Eve 1999, he helped his father shut down servers at GE Asset Management in Stamford to avoid a possible Y2K glitch.

Now it was the father's turn to be the helper, to get his son through this illness. Jim Zarifis told his son, over and over: "It's my time to worry and your time to feel better."

Jimmy tried to listen. "I tried to stay uplifted and get through it," he said.

Surgery and smiles

Four days after the cancer was diagnosed, Jimmy had surgery at Westchester (N.Y.) Medical Center to remove the tumor and to relieve the pressure on his brain.



The News-Times/Chris Ware

At home Jimmy's mother Elizabeth and his sister Michelle help prepare Jimmy's medication for the effects of chemotherapy.

Afterward, Jimmy's left side was paralyzed. He could not speak. His eyes wouldn't focus.

For six weeks, Jim or Elizabeth or both were at the hospital all the time. Friends stayed with the younger kids at home, taking them to school, taking Steven to baseball games, taking Michelle to ballet lessons and even planning her birthday party.



The News-Times/Chris Ware

During the summer months of 2004, Jim and Jimmy would regularly swim at the public pool. The effects of osteonecrosis in his hip made walking difficult. To reduce atrophy in his legs, Jimmy would exercise in environments that didn't put stress on his body.

The parents barely slept. They washed their son, changed his sheets, kept him from yanking the tubes and wires out of his head. Their devotion impressed Dr. Claudio Sandoval, one of Jimmy's cancer specialists.

"They're salt-of-the-earth people, these people," Sandoval said recently. "They have a good attitude. They are very much in tune to (Jimmy). Every time I saw him, there always was a smile, even though there was pain and he lost some of his gains."

Jimmy made slow progress. First he could shrug his left shoulder and left arm. Then he could move his left

wrist a little.

A few weeks after surgery, Jimmy began radiation and chemotherapy sessions to try to kill the cancer cells. "I wouldn't wish it on anybody," Elizabeth often thought.

The toxic chemicals left Jimmy drained and vomiting. But to the surprise of the hospital staff, this was not a kid who seemed to feel sorry for himself.

He smiled all the time.

He reached out to his family. Even when he could barely groan, he would force out words like, "Hi, Dad." And, "I love you."

He tried to make other people feel better.



The News-Times/Chris Ware

Jimmy looks back over his shoulder at a baseball game where his brother was playing. "Jimmy loves baseball, he loves to run," said his mother Elizabeth.

Once, a nurse came into Jimmy's room just as he was throwing up into a bucket. "How are you doing, Jimmy?" she asked. He looked up. "Great," he said. And then he went back to the bucket.

From the beginning, Dr. Avinash Mohan, then a first-year resident at the medical center, noticed something different about Jimmy. Mohan had observed that many kids with cancer sense their parents' distress and take advantage of it. "Some kids get very demanding and spoiled," said Mohan.



The News-Times/Chris Ware

From left, Steven, Jimmy and Jim, spend time together taking paintball shots outside their home.

Jimmy, however, "rarely complained," he said. "You always had to check on him because he wouldn't complain if something was bothering him."

Doctor and patient struck up a friendship. The two baseball fans would chat about each game of the 2002 World Series.

The relationship helped Mohan decide to do brain tumor research in the second year of his residency. He still e-mails the family, asks about Jimmy, shares the latest research on medulloblastoma.

"I'm very picky about who I like," Mohan said. The Zarifis family passed the test. "They're very modest people."

Six weeks after the surgery, on a rainy November day, Jim Zarifis told his son it was time to go home. "My Dad and I were so happy," Jimmy recalls.

Before Jimmy left the hospital, he carefully packed up more than 30 balloons — many with the Yankees' logo — people had given him. At home in Newtown, he pressed them in a scrapbook.

He said he didn't want to forget all the love everyone had offered when he really needed it.

Making an impression

Jimmy was home. But he was not all the way back.

The chemotherapy and radiation treatments zapped his energy. He would lie motionless for hours. Steroids taken to offset the toxins used in chemotherapy left him bloated.

Anne Marie Coniglio headed to the Zarifis home in November 2002 to help Jimmy stay on track with his classes. Coniglio home-schools students from Newtown Public Schools.

At their first tutoring session, Jimmy didn't have the energy to make it through the whole hour. Still, Coniglio left impressed. "He affects you the minute you meet him," she said. "Just his sense of humor, he's adorable."

The tumor and treatment had affected Jimmy's academic skills. Multi-step math problems

gave him problems. He put extra words in sentences.

Tutor and pupil worked an hour a day, five days a week. Jimmy made progress. "I'm sure it was hard for Jimmy but he was like, 'This is what I have to do,' and he just did it," Coniglio said. "Jimmy just never complains."

Several months after Coniglio started working with Jimmy, she suffered head and neck injuries in a car accident. At one point, she faced the prospect of getting injections to treat the pain.

She wrote Jimmy a note. "If I have to do it, I'm going to think of you. And how brave you are. Y.Y.Y."

As Jimmy's mind got stronger, he worked on his body as well. Shortly after Jimmy's return home, occupational therapist Diane Day started helping Jimmy. There were still days when Jimmy couldn't get off the couch, when he had trouble lifting his arms.

"How are you doing, Jimmy?" Day would ask. Almost without fail, Jimmy replied: "Oh, very well."

Day noticed the same things as the people at Westchester Medical Center. Jimmy wouldn't quit, wouldn't complain, wouldn't feel sorry for himself. And he constantly reached out to others.

When they lifted weights, Day would cheer on Jimmy. And he would cheer back. "Come on, Mrs. Day, you can do it."

Said Day: "He could break apart from what he's going through and care about other people."

It's been more than a year since Day last worked with Jimmy. She still thinks about him, still drops by to see how he's doing. In 20 years as a therapist, Day has worked with hundreds of patients.

But Jimmy is special. "Twenty years from now, Jimmy is someone I will be telling my grandkids about," said Day.

In the spring of 2004, Jimmy went back to Newtown Middle School to finish seventh grade. Ian Mason, his best friend, was thrilled to have him back.

Since fourth grade, the boys had forged a friendship based on baseball. Ian, a diehard Red Sox fan, even forgave Jimmy for liking the Yankees.

But now baseball — at least playing it — was out of the question. Ian was cool with that. He and Jimmy still hung out together, playing video games or doing homework. This fall, the friends will both enter Newtown High School as freshmen.

Ian knows one thing about his friend. "He just wants to be treated like a normal person."

Pain, faith and hope

Nearly two years after he began throwing up on the baseball fields, Jimmy suffered a huge setback. His hip began to hurt. Doctors first said it was a muscle pull, but the family knew it was something more.

Eventually, Jimmy was diagnosed with osteonecrosis, or bone death in his hip. The steroids had reduced blood supply to his hip joint, causing it to deteriorate.

Doctors did surgery to relieve some pressure on his hip. Still, Jimmy had to go back to using a wheelchair most of the time.

Jimmy doesn't like to talk about his hip. Doesn't like to think too much about how one day he might one day need hip replacement surgery if it doesn't improve.

But he will talk about the hurt of not being able to play ball with his friends, of not being able to run around with them. Sometimes he cries. "I always pray. Because it just gives me a little more hope," Jimmy said.

His mother prays, too. For Jimmy. For her family. For strength to cope with the heartache.

"When I see his friends running to the bus, I just remember when he used to take the bus, running to the bus, and saying good-bye," Elizabeth Zarifis said. "Those things are sad and very upsetting."

Sometimes her oldest son comes up to her, wishing for the past. "Sometimes I think my life stopped when I was 11," he tells her.

Sometimes it looks that way, too. Because of the cancer and all the medication, Jimmy has grown only a quarter-inch in three years. He's taking a growth hormone now to try to make him taller.

When it all gets to be too much, Elizabeth Zarifis thinks about how far her son has come. She thinks about her loving family, about her faith, about Jimmy's determination.

"I get strength from him because he's so good," she said. "Thank God the way he is."

Jimmy steps out

A bad hip can slow you down. It can stop you from running to first base or playing shortstop like Derek Jeter. But it can't steal your desire or douse your passions.

And it can't stop you from putting on your mitt and playing catch with your kid brother.

"He really wants to go out and play baseball so much," Jim Zarifis said. "He wants to be up and mobil."

Thanks to more therapy, Jimmy often ditches his wheelchair, instead using a walker or a helping hand. This spring, he made his first trip alone to a friend's house since getting sick.

Jimmy's mom cried after she dropped her son off. In the back seat, Michelle, now 8, told her mom not to be sad. "Mommy, we had to let Jimmy go" Michelle said. "I am so happy for him. This is a good thing, Mommy. He's playing with his friend."

Jimmy's 14th birthday was in April. He knew what he wanted to do: race around a track, losing himself in the speed. Poking around on the Internet, he found the perfect go-cart spot — Dadds Xtreme Indoor Sports in West Haven.

After arriving in the parking lot, Jimmy's friends raced for the front door. His father pulled out the wheelchair. Jimmy protested. "We'll get rid of it inside," his father promised.

After Jimmy popped a few wheelies in his chair to impress his friends, the group headed for the go-carts.

"I get the white one, that white one," Jimmy called. His father took his hand and led him to the car. The father then hopped in a two-seater with Michelle. Steven took a car in the back.

Elizabeth taped the race with a digital camera. Steven pumped his fist at her. Michelle waved. Jimmy stayed focused, slipping his car past a friend on the right, completing lap after lap.

Afterward, he grabbed his father's hand. "That was so cool, we have to come here again," Jimmy said.

"Yeah," his father said, smiling. "I think so."

Back on the track

On June 13, Jimmy returned to the track — the one at Newtown High School, where he took so many painful steps after brain tumor surgery.

It was Newtown's second annual Relay for Life. A thousand people from the community turned out to raise money for cancer. Jimmy's cousins and aunts were there.

Jim and Elizabeth Zarifis reveled in the night.

Daughter Michelle started off the night by singing the optimists' anthem "Tomorrow," from the musical "Annie." Younger son Steven bounded around the track, playing with family and friends.

Jimmy had taken part in last summer's Relay, riding his hated wheelchair the whole time. Taking part in an event that raises awareness of cancer "just seems like the right thing to do," he said.

This year, he was determined to ignore the pain in his hip. He was determined to will his legs to work.

He again had his family beside him.

Jim and Jimmy linked arms, as they have often done, and began taking steps.

Ten feet. Twenty feet.

Thirty feet came and went.

Before they were done, father and son had circled the track five times.

No, the boy just won't give up.

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