

## Brave survivor

Written by CAROL POMEDAY  
Wednesday, 17 April 2013 14:10

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### **Given a 3% chance of surviving a rare form of leukemia at age 1, Garin Karsten of Fredonia today is a sports-loving fifth grader who wants to be a Marine**

Garin Karsten of Fredonia was all smiles April 10 as he celebrated his 12th birthday.

So were his parents Stacey and Robert, who feared milestones like this wouldn't happen when Garin was diagnosed in June 2002 with Langerhan's cell histiocytosis, a rare form of leukemia that can attack multiple organs.

At least five different high-dose chemotherapies, intravenous and oral, were tried without success on the 1-year-old, who continued to smile and charm everyone who met him, his parents said.



With each relapse, his chance for survival decreased 30%, his mother said.

Garin was near death and given only a 3% chance of survival until he received a bone-marrow transplant June 19, 2003, at Children's Hospital of Wisconsin in Milwaukee.

"It feels like he has two birthdays — the regular one and the one in June," his mother said.

"The day after his transplant, just looking at him, the life was there again. I could just tell."

Garin — a fifth-grader at Ozaukee Elementary School in Fredonia who swims, bikes, plays soccer, baseball and basketball, fishes and goes on fossil-hunting trips with his father and grandfather — doesn't remember much about his early-life struggle, but he's heard the stories and does everything he can to promote organ donations.

He participated in the 2010 National Transplant Olympic Games in Madison and goes to Rainbow Camp for two days each summer for children who are transplant recipients. His photo was featured on a large Children's Hospital billboard erected at the Wisconsin-Illinois line and appeared in hospital brochures. Not only did Garin have to fight for his life, impressing medical

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teams with his spunk, but his parents fought their health-insurance carrier and Medicaid in vain to get them to cover the \$500,000 bone-marrow transplant.

Although his transplant doctors testified at an appeals hearing in Port Washington that the boy would die without the transplant, coverage was denied — by the insurance carrier because the disease was not listed as eligible for a bone-marrow transplant and by Medicaid because it was considered experimental.

“They didn’t have success stories because a lot of people don’t get that far because of the quick relapse time,” Mrs. Karsten said.

Garin’s parents worked with the Children’s Organ Transplant Association, a national organization that helps families raise money for children’s transplants. About \$35,000 was raised, Mrs. Karsten said. The hospital performed the transplant at no additional cost to the family, she said, but the account remains open for future fundraisers to pay for transplant-related expenses.

Garin has been cancer-free for almost 10 years. The Karstens hope his success story will make it easier for other children who need the transplant to have it covered by insurance.

Garin was an active baby who enjoyed playing with his half-brothers Tyler and Alex, now 22 and 18.

His mother had noticed a symmetrical rash on his neck and groin but it wasn’t until his grandmother called that Garin was acting strangely that they became concerned. The couple now know the rash is an early symptom of the disease.

Mrs. Karsten took her son to his pediatrician, who noticed the child’s liver was enlarged and ordered blood tests that showed his white blood cell counts were extremely high.

“He came back in the room and said, ‘You go home, pack for a couple of days. I’m calling Children’s Hospital that you will be there within the hour,’” Mrs. Karsten said.

After Garin was diagnosed with Langerhan’s histiocytosis, chemotherapy was started. He was in the hospital for 18 days.

“The first year, we spent every holiday at the hospital,” Mrs. Karsten said. “Garin always wanted to be in a room where he could watch the (Flight for Life) helicopters. One time, the crew got him and took him to the helicopter.”

Garin was put on the waiting list for a bone-marrow transplant.

His parents were matches, but not perfect ones. Four potential donors who were exact

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matches were found.

The bone marrow came from Kevin, a 36-year-old man who lived in Mississippi and had been on the donor list since 1993.

Garin, who had been in the hospital since May, was released in mid-July when his white blood cell count was in the normal range.

Initially checked every day for possible rejection or infection, Garin was slowly weaned to where he now has an annual check-up.

Garin has matter-of-factly dealt with complications that have arisen from the treatments, his parents said.

Small for his age, the boy has given himself a daily growth-hormone injection for four years.

Two years ago, Garin started falling and it was discovered he needed metal plates to stabilize his knees.

“I was mad because I had to miss soccer camp,” Garin said.

The plates were removed in November.

Last year, Garin had cataract surgeries in both eyes and now wears glasses.

Kevin contacted the family a year after the transplant when he was given their name and phone number. Garin has developed a long-distance relationship with the man who saved his life and hopes to go fishing with him someday.

“He said he doesn’t have children and he feels like Garin is a son,” Mrs. Karsten said. “We joke that if a blond, blue-eyed boy shows up on his doorstep, he won’t be able to deny him.”

Garin now has two DNAs.

“If it’s a hair test, he has our DNA, but if it’s a blood test, he matches Kevin,” Mrs. Karsten said.

Looking to the future, Garin said he wants to join the Marines.

“I want to protect the country and my family,” he said.

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Image Information: State pins from other athletes were collected by Garin Karsten at the 2010 National Transplant Olympic Games in Madison. Photo by Sam Arendt