THE

CrossFitJOURNAL

Suffer the Children

CrossFit unites its global community in the fight against catastrophic children's illnesses. Chris Cooper reports.

By Chris Cooper April 2013



When you're 6, you don't usually know much about steroids.

A 6-year-old mind is drawn to Barbies—plastic perfection and flowing hair. When confronted by baldness, hemoglobin and transfusions, the young grow up pretty quickly.

1 of 7

Dexamethasone is a steroid used during long treatments of chemotherapy. It prevents inflammation around tumors, which allows other chemotherapy drugs to penetrate more efficiently. It reduces dizziness and fatigue but can cause mania and mood swings. Though six times as strong as the common steroid prednisone, it's viewed as the preferable alternative for children because it doesn't make them as nauseous.

Emma just calls them her "crazy pills."

Bad and Good News

At age 3 in 2009, Emma began having joint pain and diarrhea. Her parents, Marcy and Mark Heppner, thought it was a growth spurt. Her doctor thought it was strep throat.

Two months later, Emma had become too lethargic to get off the couch. Her legs hurt.

"We rushed her to a pediatrician. They took some blood. Her hemoglobin was 2.7 out of 10," said Marcy. Thanksgiving 2009 was spent in hospital. Emma was trussed up and given six consecutive blood transfusions. She was finally released on a Thursday but scheduled for blood testing the following Monday, and then, because her white-blood-cell count was elevated, for the Monday after that. And the next Monday. And the next.

Alarmed, her doctors scheduled a bone-marrow aspirix. Three days after her fourth blood test, Emma had a needle pierce her bone to remove some marrow for testing.

"We were told we'd find out within a week," Marcy said. "Ninety minutes later, our doctor came in and said, 'I have good news and bad news.""

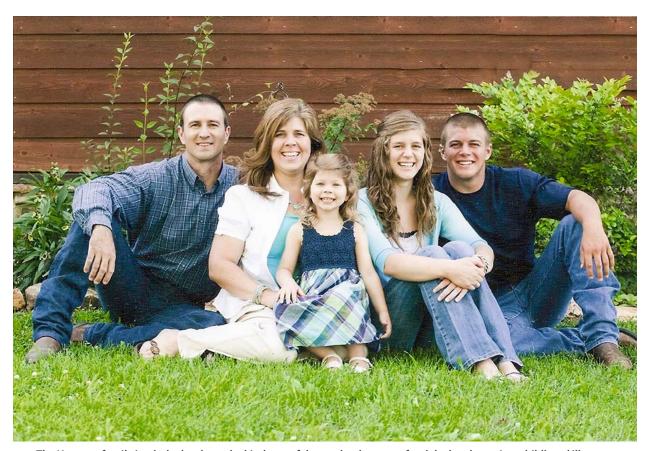
The bad news: Emma had acute lymphoblastic leukemia.

"We cried for 10 minutes and then remembered that there was some good news," Marcy said.

The good news: a free children's research hospital was only four hours away.



At the age of 3, Emma was already in a fight for her life.



The Heppner family is whole thanks to the kindness of those who donate to fund the battle against childhood illnesses.

The Price of Recovery

After her diagnosis, Emma and Marcy had only hours to prepare for a move to St. Jude Children's Research Hospital.

"They sent an ambulance to get us. It was too critical for us to drive ourselves," Marcy said. "I came home to take care of the animals, and to break the news to our son, and to pack our bags for eight weeks to travel to Memphis with Emma. You're packing up everything—your bills, your clothes, your computer. At 1:30 a.m., Emma and I got into the ambulance and drove to Memphis."

It was Dec. 17. At 5:30 a.m., Marcy and Emma were greeted by a full team.

"Within an hour, we had 10 different doctors and nurses coming in. It's a research hospital; they want to know detailed information on every symptom," Marcy said.

The constant attention was almost a relief: there simply wasn't time to worry between visitors. One of the most memorable, though, wasn't a doctor.

"Within 24 hours, I had a social worker come in and ask if I had a minute to talk," Marcy said. "She explained about St. Jude: that their sole purpose is to take care of Emma. We wouldn't have to worry about receiving a bill. We didn't have to worry about anything."

"Emma's our very expensive child, but we've never paid one cent."

—Marcy Heppner

The average treatment period for childhood leukemia is 2.7 years.

"At a regular hospital, they bill your insurance company, and whatever's left is on you," Marcy explained. Emma would need a blood transfusion every month, at US\$10,000. She'd have additional issues: a blood clot in her bladder, plus the high-dose chemo and the daily testing.

"We have two kids in college," Marcy said. "You're thinking, 'My kids are going to have to drop out of school.""

She added: "Emma's our very expensive child, but we've never paid one cent. They never stop to think what the cost is. If it's important, they do it."

Jacob is Emma Grace's big brother. A football player at Central Methodist University, he was introduced to CrossFit while doing an internship at Fort Leavenworth, and he was hooked.

He was playing football when he received the news about Emma.

"When the diagnosis first occurred, I didn't have the adult mentality to think a couple steps ahead of the game," Jacob said. "First off, I didn't know about the cost of medicine. I don't think it was until a week later that we realized that this was going to drill us—hard. I might not be able to finish college. I was getting good scholarships, but it wouldn't be enough. Would my dad be able to go back and forth to Memphis to visit?"

The no-cost treatment meant Jacob and his sister, Sarah, could finish school and start their careers. Sarah is studying political science and national security and intelligence at Fairmont State University in West Virginia.

"I would have had to choose between my little sister or furthering my education. What would any big brother choose? It took about a year for me to realize what a huge opportunity I had," Jacob said.

So where does the money come from?

CrossFit for Hope

It costs \$1.9 million to turn the lights on every morning and run St. Jude for a day. Some celebrities contribute, but the majority of donations are just from average folks around the world. Incredibly, 70 percent of all donations made to St. Jude are for \$30 or less.

Thirty bucks isn't much, and it certainly doesn't buy much in a hospital. That's where the global CrossFit community comes in. There are now more than 6,000 CrossFit affiliates. Imagine if 10 members in each affiliate decided to donate

just \$30 to CrossFit for Hope. That's the price of a skipping rope. Do the math, and you've suddenly got \$1.8 million. If you get 20 members per affiliate, the number doubles to \$3.6 million.

CrossFit for Hope is the umbrella for several initiatives all designed to help people in need.

CrossFit's goal last year: to raise enough money through the Hope fundraising campaign to pay St. Jude's costs for a single day.

The community succeeded.



St. Jude was just one beneficiary of the CrossFit for Hope campaign that unites the global CrossFit community.





The charity of others takes the financial burden off families and allows them to focus on caring for sick members rather than worrying about money.

This year, the goals are loftier.

CrossFit for Hope is the umbrella for several initiatives all designed to help people in need. In 2012, St. Jude was a major beneficiary. Almost \$300,000 has been raised through the Hope for Kenya initiative, which funds health and education improvements near Mombasa. Already in 2013, CrossFit for Kenya raised an additional \$60,000

through \$5 donations made during athlete registration for the CrossFit Open. That money will fund the building of four new schools in a country where education adds years to life expectancy.

"We have a bunch of fit, intelligent, caring people in this community, and they rally," said Jimi Letchford of CrossFit HQ.

Indeed, the global CrossFit community is quick to take up the fight when called upon.

"Most foundations spend the majority of their time trying to attract donors," said Josh Murphy of CrossFit HQ. "We don't have that problem."

The best part is that every dollar raised through CrossFit for Hope goes straight to the charity.

"At the end of the day, it's a dollar in, dollar out. If we raise a dollar, it's going to the cause," Letchford said. "CrossFit HQ salaries the people working on Hope, pays for travel, covers all the administration. If a dollar comes in and it costs us 30 cents to earn that dollar, HQ pays that 30 cents. We're not taking it back. HQ believes in Hope and contributes out of its operating fund to make sure we have a high efficiency."

Letchford added that covering the overhead to get donated funds to where they're needed is simply how CrossFit Founder and CEO Greg Glassman approaches charity work: "It's always been like this."

Albany CrossFit was the top affiliate fundraiser for CrossFit for Hope in 2012, raising almost \$30,000.

"We just talked about it incessantly: before every class, on our Facebook group, on our blog," said Jason Ackerman, owner of Albany CrossFit. "We ran five events that were specific fundraisers. We auctioned off training with coaches, held raffles, ran a talent show. We have cash jars. We ask if people want to add a dollar for St. Jude when they buy supplements."

Ackerman's fundraising goal in 2013 is \$100,000.

"CrossFit has allowed me, my coaches and our athletes to live better lives. When the opportunity came to do something that (CrossFit) felt strongly about and was backing, it was really important for me to get behind it, and then our coaches got behind it, and all of our athletes as well," Ackerman said. "When you get 200 of your members to raise \$500 each ... that's how you get to \$100,000."



The value of research: 50 years ago, Emma would have had a 4 percent chance of recovery.

The survival rate for leukemia is now 94 percent.

New Hope

"Every doctor and nurse was happy when they declared Emma to be in remission," Marcy said.

That was 50 days into treatment. The next two-and-a-half years were a waiting game; without an immune system, Emma was sick often and couldn't undergo chemotherapy. She was put on steroids so she would be strong enough to survive the other medicines. It was a constant balancing act, with some medicines propping her up to take others.

On July 10, 2012, Emma's chemo port—a hole in her chest through which medicine is delivered—came out.

"They have a no-more-chemo party. The doctors came in and sang a song. They threw confetti on us. We had a cake," Marcy said.

After her last dose of dexamethasone, "Emma put the bottle in a plastic bag and slammed it with a hammer," Marcy said.

Though finished treatment, Emma won't be declared cancer-free until five years after her remission date. She'll continue with yearly checkups until she's 18, when she can elect to remain in the research cohort into adulthood.

After her last dose of dexamethasone, "Emma put the bottle in a plastic bag and slammed it with a hammer."

Emma, at 6, has lost seven friends to cancer and is now a vocal advocate.

"She would see a child looking at her when she was bald. She would literally walk over and say, 'Let me tell you why. I have cancer and it made my hair fall out, but it's going to grow back," said Marcy.

And the rest of the family is on board, too.

At college, the Heppner kids are the first to sign up for any blood drive.

"Those saved their sister's life," Marcy said. "Jake did a bone-marrow drive on campus."

Jacob is paying it forward by participating in communityservice programs, earning him a selection to the Allstate AFCA Good Works Team (CMU's Heppner Selected to 2011 Allstate AFCA Good Works Team).

Jacob also volunteers to coach at Iron Major CrossFit, inside Fort Leavenworth.

"We have a not-for-profit affiliate, and I help out there daily. It's a good opportunity to enlighten some of our officer candidates about fitness so they can go back to their brigades and teach them," he said.

You can bet there will be a CrossFit for Hope event at Fort Leavenworth this year.

"It's not just us lifting. It's us contributing. That's what makes it awesome," Jacob said.

A Comeback Victory

In 50 years, leukemia went from a 4 percent to a 94 percent survival rate.

Go beyond the percentages: 50 years ago, 96 out of 100 kids with leukemia would perish and leave gaping holes in families. In 2013, 94 out of a hundred can expect to survive.

"We're within the final few yards of the largest come-frombehind underdog victory in history," Marcy said.

"We're within the final few yards of the largest come-from-behind underdog victory in history."

-Marcy Heppner



Emma, alive and well.

CrossFit is part of that comeback, and it will be part of the victory in the fight against catastrophic children's illnesses.

When Jake saw the poster for CrossFit for Hope, he was thrilled and told his mother about it. Marcy felt obligated to find out more about CrossFit.

"If they're going to donate to save my daughter's life, I have to know all about it," Marcy told him.

She's not shy to share credit with anyone who raises funds to support the fight.

"When you as a community give, you provide hope and a cure and you take ownership of a child. Then you're a part of Emma's treatment and a part of her cure. You should take ownership of that," Marcy said.

To find out more about, CrossFit's fundraising efforts, visit CrossFit for Hope.



About the Author

Chris Cooper is a writer for CrossFit. He owns CrossFit Catalyst in Sault Ste. Marie, Ont.