





# Cancer: 5-year-old 'the one who keeps it light'

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estimated at about 20 percent.

"Many of the awful, awful drugs Chase had were adult drugs that they're experimenting with in pediatric doses," Ellie said. "There are quite a few pediatric cancer treatments where the side effects border on barbaric because there are not advances in this area."

Luckily, the only two treatments known to cure Chase's cancer worked. In August 2013, there was no evidence of the disease.

"That was just a huge relief," Bob said.

Now, as they try to find their new normal, the family of six is working to educate others about pediatric cancer and the need for more research.

This month, they were presented with the perfect opportunity to do just that. Chase was named one of five ambassadors nationwide for the St. Baldrick's Foundation, a group best known for getting volunteers to shave their heads as part of the serious business of raising funds to focus strictly on research for cures for childhood cancer.

"Our goal is to be able to share Chase's story and encourage where we can, and then step in kind of wherever they need us to," Ellie said. "That was in my heart all along — even before St. Baldrick's — to use our story to encourage other people."

## 'Love for life'

One in five children diagnosed with cancer in the U.S.

will not survive. Additionally, more than 80 percent of survivors will suffer from severe or life-threatening conditions from the cancer treatment.

For instance, Chase developed sores down his throat and into his stomach from the treatments, which prevented him from eating solid foods for about 16 months.

Doctors also say Chase's spine will never fully develop due to the radiation treatments, and that will give him the appearance of having abnormally long arms and legs.

"To a certain extent we'll never know what damage the tumor caused, what damage treatment caused, and radiation came at a neurological price as well," Ellie said. "We found we were often in these situations where treatment might kill him, but the cancer surely will."

On one of the roughest days, Ellie recalls walking from the Ann & Robert H. Lurie Children's Hospital of Chicago to Lake Michigan and taking a moment to read from the book of Psalms.

"I just remember feeling so weighed down," she said. "I remember praying and asking God if I was going to need to let go of my son and to help me do that if it comes to that."

Life is a lot different now. On a recent afternoon, Chase and his brothers keep talking over each other, trying to get Mom's attention. One minute they're seated at the kitchen table, coloring pictures with crayons. The next moment they're running after each other and shrieking.

There's laughter as they



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**Watch the video:** "I'm a survivor," says Chase Ewoldt, 5, of Wheaton with his mom, Ellie. Together they explain his ambassadorship at [dailyherald.com/more](http://dailyherald.com/more).

make silly faces at each other, then short bursts of tears over who gets to play with a favorite toy.

It's chaotic, but to Ellie and Bob it's perfect — especially because Chase is right in the middle of it all, keeping up with his brothers and enjoying every minute with them.

"He has this love for life that the cancer didn't change for him," Ellie said.

## Need for funding

The Ewoldts' involvement with St. Baldrick's is very personal.

Shortly after Chase was diagnosed with cancer, his pediatric neuro oncologist, Dr. Rishi Lulla, received nearly \$100,000 from the foundation to research pediatric brain tumors.

Blood, urine and spinal fluid samples from Chase's routine tests have been used in Lulla's study, which is

examining biomarkers in pediatric patients with brain and spinal cord tumors.

Such work, Lulla said, "could not be done without their support. We really rely on organizations like St. Baldrick's and others to help us do this."

According to the St. Baldrick's Foundation, childhood cancer research funding accounts for less than 4 percent of all cancer research funding provided by the federal government.

Last year, the foundation donated more than \$27 million to research. Since its inception in 2005, the foundation has provided \$100 million in childhood cancer research grants.

While many other cancer organizations fund patient support groups, transportation to treatment, places for families to stay during hospital visits and programs to help patients look and

feel better, St. Baldrick's is focused solely on childhood cancer research.

"They're putting money into the hands of doctors," Ellie said. "That directness is of great importance."

Lulla said in the last 20 years there have been "relatively few" drugs designed specifically for pediatric cancer, partly because there is reluctance to develop expensive new drugs that would help only a small percentage of the population.

Still, Lulla said he is optimistic because doctors' understanding of pediatric tumors is increasing, and he hopes as they learn more they'll be able to partner with drug companies more.

## 'Moment by moment'

St. Baldrick's gets a lot of publicity about its head-shaving events, but the Ewoldts want people to know there are plenty of other ways to raise money.

"I've actually talked with people before who said, 'Oh, I could never be involved in that because I really don't want to shave my head,'" Ellie said. "You don't have to shave your head in order to be involved in this."

Still, the Ewoldts hope to take Chase to some local head-shaving events this year so he can put a face to the cause.

"When people see Chase, can even touch his head and hear his stories, hopefully that will make it very real to them, what they're doing," Ellie said.

"Research can sound very

clinical, and it can just be very out there and appear very cold, but we can put flesh and blood to the research with someone like Chase," she added.

Lulla said Chase was a great fit to be a St. Baldrick's ambassador.

"He's such a charismatic person, it's hard to not be interested in him," Lulla said.

In the last three years, Lulla said he saw Chase through "a lot of ups and a lot of really, really bad downs," but even in the intensive care unit he managed to crack a bit of a smile.

"He actually is the one who keeps it light for everyone," Lulla said.

Despite the good news of August 2013, Chase may not be completely out of the woods. Some of his latest MRI results showed several growths forming slowly in the original tumor bed in his brain.

"We walk into every MRI wondering, 'Is this the moment that we're going to have to restart treatment?' or 'Are there even treatments that can be used?'" Ellie said. "There's a large question mark in front of us."

For now, however, the family is living "moment by moment" and thinking about what they can do to advance awareness for childhood cancer research in the next year.

Chase just keeps smiling. "I'm a survivor," he says from his mom's lap.

Ellie nods in agreement. "He's in great shape," she said. "We're just blessed in our today, and that's all we have."