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Kids & cancer

By [VIRGINIA ANDERSON](#)

The Atlanta Journal-Constitution

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Researchers can count the number of new cases of pediatric cancer each year — about 12,000. They cannot, however, measure its emotional toll on children and their families and friends. And researchers cannot put experimental findings into practice quickly because of the huge expense of clinical trials. In the face of those challenges, many Atlantans are organizing to help those who are suffering and those seeking a cure. This article shows how the family of a child who died of cancer has transformed its tragedy into hope for others.

Killian Owen was 9 years old when he died from leukemia two years ago, but he lives on today in millions of ways. And, he may help other children win their battle against childhood cancer, even though medicine moved too slowly for him.



Owen family photo
([ENLARGE](#))

This month — Childhood Cancer Awareness month — his family is finding joy in knowing that the millions of cells taken from Killian before he died are helping scientists start three clinical trials on a new class of drug that may cure some childhood cancers.

And, they feel happy that a charity that the family started in Killian's honor is helping to pay for the research.

"I can't let this happen to other children," Killian's mother, Grainne (pronounced GRAN-ya) Owen, said. "If there's something we can do to stop it, that's what Killian would want me to do. "

Childhood cancer research does receive \$165.9 million from the National Cancer Institute and millions more

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Killian Owen (right) struggled valiantly against a fatal disease. Above, he plays a video game with his twin, Garrett, at the National Cancer Institute in Bethesda, Md., in June 2003 as he awaits an experimental drug treatment. He died that July.






LAURA NOEL/AJC STAFF
(ENLARGE)

Grainne and Clay Owen (standing, center and right) share memories of Killian with their sons Pierce (from left), Garrett and Finn at their Marietta home.

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from private sources. Still, advocates believe that is not enough, because funding levels have only slightly increased in recent years — and more than 2,000 children still die annually from the disease.

Doctors believe that life-saving drugs are in the pipeline, but a shortage of funding means many of the drugs don't get to the children fast enough or at all. A sick child in Atlanta, for example, could not participate in a limited research trial in Oregon without enormous expense.

And because any drug developed would only apply to a very small market share — about 12,000 new cases are diagnosed each year nationwide — it's hard to get research off the ground with pharmaceutical companies. Before a dollar is even spent, possible childhood cancer cures are often seen as cumbersome, unprofitable ventures

Last spring, the Institute of Medicine issued a report that urged more public-private partnerships in funding for childhood cancer and also for less delay in getting badly needed drugs to the patients who desperately need them.

"Money is a big issue," said Dr. John Bergsagel, a pediatric oncologist at Children's Healthcare of Atlanta who was also Killian's doctor.

He wouldn't give up hope

Killian and his family are helping.

When Killian relapsed with acute lymphocytic leukemia, in spring of 2003, doctors had nothing more to offer.

But after weeks of slicing through red tape, doctors at the National Cancer Institute, in Bethesda, Md., gained permission from the Food and Drug Administration to test an experimental drug, called BL22, on Killian. The problem was it had only been tested on adults and doctors didn't know what dosage to give Killian and how it might affect the little boy.

"Doctors were hovered around, watching his every move and every monitor," Grainne Owen said. "There were so many, they had to stand in the corridor."

But it was too late for Killian to be cured. Within a

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month, doctors told his parents that he would not survive.

Owen did not want to tell Killian, who had refused to give up hope. Doctors told her she must. She struggled with how to walk into Killian's hospital room and tell the child — who had been talking about how he couldn't wait until fourth grade started in a few weeks — that he was going to die.

"His grandmother had died, and so we had been talking about her being in heaven," Owen said. "And I said to him, you know how you've been talking about Nana a lot? Well, Nana may be coming down to get you. And he said, 'No, Mama, no. Don't talk about it.' And so we never mentioned it again."

Their angel is happy now

Killian died July 27, 2003.

And after a year of grieving, his mother decided it was time to move on.

"We were so sad, and we missed him so much," said Owen. "There was something about not seeing him for a year that was really hard. But I said to [his three brothers] that probably we shouldn't be feeling so sad because Killian's an angel now, and very happy. And I thought we should focus our attention on helping other children with cancer."

Owen started Coaches Curing Kids' Cancer and has raised about \$120,000 since Sept. 9, 2004. The money goes entirely to pediatric cancer research.

The concept of the charity is simple: instead of giving youth sports coaches an end-of-the-season gift, give them a certificate saying that a donation was made in their honor to Coaches Curing Kids' Cancer. They also get a T-shirt. The Owen family hopes the concept will spread. It could include teachers, choir directors, scout leaders and anyone who is typically honored with a gift from a group.

"It could even be for birthdays," said Owen. The trials that start this month in hospitals in Atlanta, Portland, Ore., and Baltimore will be funded in part with this money. And, they started in part with knowledge gained from Killian's cells.

Those cells were taken during his fight with leukemia and now have been used repeatedly in a National Cancer Institute lab in Bethesda to study whether a version of BL22, called LMB2, may help other children.

Based on how Killian's cells have responded in a lab to LMB2, doctors have expanded its use to more than two dozen children nationwide.

Researchers and doctors at NCI are grateful for and somewhat in awe of the Owens' efforts.



"These families go through such enormous grieving," said

Atlanta oncologist Bergsagel. "To think that they have done this in the face of their loss is amazing."

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