



# selfless Victory

*Above:* Children's cancer patient Nicholas Kuelbs, 6, sells his handmade crafts at businesses near his home and donates the money to Children's. Through his sales of crafts, pickles and pizza, the Kuelbs family has raised more than \$10,000 for the hospital.

*Opposite:* Picking cucumbers from the family garden was a favorite activity for Nicholas during his chemotherapy treatment for leukemia in 2003. When Nicholas felt well enough, he would help wash the cucumbers and pack the jars for making the cucumbers into pickles. As a result, Nicholas came up with the idea to sell the pickles as a fund-raiser for Children's.

Nicholas Kuelbs is a typical 6-year-old most days, running all over the house and yard, swimming, playing catch and bouncing on the bed with his younger brother, Noah. But he is serious about two things: his cancer treatment and his fund-raising efforts.

“Almost every week, Nicholas brings me an envelope full of cash and tells me, ‘It’s for the research.’ He is just a really cool kid,” said Dr. Janna Journeycake, an oncologist on the medical staff at Children’s who has worked closely with Nicholas since he was first diagnosed with acute lymphocytic leukemia (ALL) in the spring of 2003.

Nicholas lost his hair, gained weight and experienced other short-term side effects during his initial month of chemotherapy. But instead of focusing on the challenges of his own treatment, he found ways to help fellow patients, and

his age, are far more obvious than the treatment port in his side as indicators of what he’s been through.

Each year nationwide about 2,000 young children are treated for ALL, a rapid-onset cancer of the immune system in which the body makes too many immature white blood cells, called blast cells, which clog up blood cell production in the bone marrow. The clogging prevents proper development of red and white blood cells, and platelets in the blood, causing slow healing, bruising, anemia and frequent infections.

Chemotherapy treatment involves injecting or ingesting chemicals into the

it appears gone, it stays gone. Dr. Journeycake explains that “it’s like nurturing a garden that’s full of weeds: You clean out the weeds, and the garden looks beautiful. But unless you keep adding fertilizer, sow good seeds and stay watchful to keep the weeds out, they will come back quickly and choke out the garden. Ongoing care is like putting grass seeds down to help the good cells grow up.”

Pat Satterwhite, a hematology-oncology nurse, or “Nurse Pat” to Nicholas, has been impressed with how much he has grown through the care he has received at Children’s.

“Nicholas has been delightful,” she said. “He’s doing very well but has had the normal challenges of a kid whose life was suddenly spun out of control, and so he needs a strong routine.”

Initially, Nicholas had a very hard time coping with his treatment because he didn’t understand it. But he improved immensely after Dr. Journeycake took the initiative and wrote him a letter outlining treatment rules and explaining what he could and couldn’t do, who every staff member was, and why they did their jobs the way they did.

“I told him it is okay for him to cry if

# A preschool cancer patient looks past his own illness and raises money to help other children

has raised more than \$10,000 for Children’s. Now fund-raising is a way of life for him and an integral part of how he deals emotionally with his cancer experience. In his own words, he is “trying to make kids free.”

## Personal growth

**N**icholas is about halfway through the 30 months of low-intensity treatment that follow remission, the point where the body is free of detectable cancer cells. His selflessness, maturity and personal discipline, unusual in someone

bloodstream to break down and inhibit the spread of rapidly multiplying, possibly cancerous cells. Hair cells, which are similar to cancer cells in regard to how quickly they multiply, often are broken down as well, causing hair loss as a side effect. Hair loss shows that the chemo is working.

Because leukemia exists in the blood throughout the body, long-term therapy is required to ensure that once







*Left:* Nicholas was diagnosed with acute lymphocytic leukemia, a rapid onset cancer of the immune system, in the spring of 2003. Now in remission, he is about halfway through the 30 months of low-intensity treatment that follow.

*Opposite (top right):* Nicholas, right, and brother Noah make pizzas for guests at Joe's, a Southlake pizzeria, as a fund-raiser for Children's.

*Opposite (center):* Nicholas, top, and brother Noah with mom Tyler at the family's Southlake home in summer 2004.

he needs to when we prick him for tests, but that we still have to do it, so he isn't allowed to fight us," Dr. Journeycake said. "We try to keep treatment as friendly and routine as possible, with the same orders, the same doctors, the same nurses, the same child life specialists and so on."

Nicholas returned with rules of his own: His main rule is that staff members are not allowed to joke around while he is getting his treatments. They can joke with him afterward, but to Nicholas, treatment is no laughing matter.

## Pickles and pizza

Nicholas is an example of how virtuous a person — especially a child — can be in the face of adversity. While recovering from his initial chemotherapy, instead of lying around and watching television or moping about his disease, Nicholas began his first fund-raising project for Children's: He sold pickles.

"It was perfect because we had to stay inside a lot, and it became a really fun project," said Tyler Kuelbs, Nicholas' mother. "On the days that he felt good and it was cool enough, we would go outside and pick the cucumbers. Nicholas would wash them and scrub them and pack the jars."

"Then Nicholas said, 'Mom, why don't

# Nicholas' projects have raised more than \$10,000 for the hospital and that total continues to grow.



we sell some of these pickles and get some videos for the hospital?" she said. "So we just sold the pickles for whatever people wanted to pay — we didn't really have a price. We sold some pickles for \$20, and we sold some pickles for \$1,000."

Nicholas did all the work. He made the pickles, handled the money from the sales and chose the videos for the children. But when pickle season was over, he had other ideas for ways to help children.

Some of Nicholas' only smiles during treatment came when pizza would arrive at the hospital for him from Joe's, a Southlake pizzeria frequented by the family. So in mid-September, when he was feeling better, he put on a pizza fundraiser. He and Noah spent the evening in the Joe's kitchen making \$100 pizzas for the guests, with all the money going to Children's.

"I think I could spin the dough on one finger if the place was all clear," said Nicholas, whose favorite part is tossing the dough.

Nicholas' parents have been supportive of his efforts, and his mother is joining him in finding ways to help Children's. They were part of the annual Children's Cancer Fund Style Show, which raises money for pediatric cancer research at UT Southwestern and Children's. Nicholas and Noah both plan to volunteer as

models again next year.

"A big part of how kids fare in treatment is the family attitude," Satterwhite said. "Treatment is no fun. It's a big inconvenience; your whole life is upside down; but it's got to be done. If the family is overwhelmed, then the kid is overwhelmed, but Nicholas' family has been awesome."



## Can-do attitude

The Kuelbs family spent part of the summer in Whitefish, Mont., where Nicholas got the chance to ride horses and wave-runners, go hiking and fishing, and see grizzly bears and deer in the wild. The trip was confirmation to Nicholas, his family and his doctors of how well he has responded to treatment.

Nicholas went back to school in the fall, but still is continuing his long-term effort of raising money for pediatric cancer research. He places boxes of crafts at local businesses, where people select crafts and leave donations. The most successful crafts have been the hearts, crosses, wands and picture frames handmade by him and Noah. The money from these crafts is what he brings to Dr. Journeycake and Satterwhite when he comes to Children's for follow-up visits. Nicholas' projects have raised more than \$10,000 for the hospital and that total continues to grow.

The effectiveness of both Nicholas' recovery and his fund-raising effort seems due to his indomitable spirit and contagious altruism. When asked what the hardest thing about fund-raising is, his response is simple: "There's no hard part in it."