

# Lafayette boy inspires parents to help other acute lymphoblastic leukemia patients

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Contra Costa Times

POSTED: 08/22/2013 12:17:58 PM PDT | UPDATED: 3 DAYS AGO

LAFAYETTE -- One day, seated in the Oracle Arena at a Golden State Warriors' basketball game, a 4-year-old boy showed his father a sore spot on his wrist. Soon thereafter, their world would change forever.

The boy, Nicholas Colby Gilbert, would soon be diagnosed with high-risk acute lymphoblastic leukemia, a vicious form of cancer that mostly strikes young children. He and his family -- parents Lamont and Sheila and Nicholas's older brothers Christopher, Timothy and Matthew -- began an epic battle with a disease whose rarity limits research dollars and whose cure remains hidden in the future.

Nicholas, whose family lives in Lafayette, underwent chemotherapy and eventually, an unrelated matched bone marrow transplant. Because his father is African American and his mother white, there were few matches in the donor base. Even the match found by good fortune turned into a pins-and-needles operation when a national incident grounded flights and Nicholas's bone marrow-depleted body was held in limbo. Gilbert cannot recall the specific national incident, but will never forget the near disaster as his son's carefully choreographed bone marrow handoff was threatened, then completed successfully.

Success was short-lived, and from the pinnacle of hope Gilbert felt as he finally thought, "My son's going to beat this," Nicholas's body rejected the transplant. The family refused to plunge with his prognosis.

"I never wanted to parent him as if he were going to die," Gilbert says. Nicholas did succumb, however, in May 2006.

Seven years later and still subject to sudden bursts of tears, he hasn't changed his tune. But now, his youngest "child" is the Nicholas Colby Fund.

The NCF provides personalized experiences and support for child patients and their families at three Bay Area hospitals. From an Oracle Arena luxury suite offering first-rate viewing of Warrior's games, Disney on Ice and other performances to backpacks filled with toys and food



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Lamont Gilbert shows off a book about bone marrow transplants featuring his son Nicholas, who...

and basketball clinics led by NBA players, all services are meant to uplift and affirm the joyful spirits of children. Gilbert said his son reached out to others, even on his darkest days. In the hospital, photos show a grinning Nicholas, strapped into a radiation vest -- and remembered moments include his giving away his toys to other children. "Nicholas taught us about giving," his mother says.

"Partly, it's selfish," Gilbert admits. "The more I do with the fund, the more I feel his presence with me every day. But I would gladly have done it without having experienced what happened to our son."

A leadership consultant with CSAA Insurance Group, Gilbert's vocation fits his charismatic, old-school manners like a glove. He often speaks at conferences where his avocation -- adding to children's happiness -- and his work life intersect. Influence and innovation create community, Gilbert suggests business leaders he meets often forget their Fortune 500 companies to zoom in and admire the NCF's ever-widening circle.

"We're boutique: we do five things well," he says. "The Warriors have been partners from the beginning. They do the clinics, special visits in the luxury suite -- and they sent their mascot to Nicholas's memorial service."

Every Jan. 27, Nicholas's birthday, they put his picture up on the Jumbotron and announce, "Never gone, never far, in our hearts and souls forever." Lafayette grocer Diablo Foods fills the nutrition packs; retailer Papyrus supplies books and journals; Danville's Games Unlimited donates toys. Webmastering and other services are pro bono and as a result, all NCF experiences are free to the recipients.

Gilbert says Nicholas's death bundled his family together. The heightened awareness of life's preciousness released his compassionate energy. "I want to be a good person and do the right things so that I can be with him," he says. Gilbert believes his son is in heaven and says, "I have to keep my faith strong because if I break that trust of loving God, then that means heaven's not for real and I wouldn't know where Nicholas is."

His faith ties him to his son and provides strength, but there's one aspect of running the fund that causes him to crumble.

"I can talk about this, but I can't get close to the kids. Once, I had to pick up one of the kids and I almost could never put him down," he says. It is his -- and the children's -- blessing, that Sheila has opposite capabilities. Declining active participation in an interview, she embraces every child and makes each one feel they are "most special in the world," Gilbert says.

There is no dwindling of support for NCF, even after seven years. There's talk of partnering with the NBA to have an NCF luxury suite in every city. "Maybe I'll get that to happen when I retire," Gilbert says.

Nicholas died holding a friend's hand after groups of 20 visitors rotated through his room in 10-minute shifts.

"One little boy can change your life and help you realize what it means to be good," his father says. "By showing us how potent giving can be, he empowered us all."



Lamont Gilbert shows off a book about bone marrow transplants featuring his son Nicholas, who died seven years ago of a rare form of leukemia. Gilbert now heads the Nicholas Colby Fund, an organization that has provided a ray of sunshine for legions of terminally ill children and their parents, during an interview at his home, Sunday, Aug. 11, 2013 in Lafayette, Calif. (D. Ross Cameron/Bay Area News Group)