



A CHANGE OF HEART

At only 33, Lisa Savarese was near death when a grieving family she'd never met made the emotional decision that saved her life

Next to the baby monitor on Lisa Savarese's bedside table in Freeport, New York, are no fewer than 21 framed photos. Most display the sort of pictures you'd expect of a mother of four: shots of husband Vinnie, 40; their 1-year-old twins, Alexa Rose and Samantha Danielle; and Lisa's children from her first marriage, Joseph

and Nikki-Taylor, 14 and 12. But nestled among these family portraits is an unexpected image: a portrait of a handsome, dark-eyed teenager wearing a crucifix. He is Daniel Gianadda, and he died in 1999 on the day of his high school graduation. It is his heart that beats within Lisa Savarese's 40-

By MARGARET RENKL

Photographed by JAMES REXROAD

year-old chest. Without Daniel, Lisa's adorable, high-energy toddlers

Lisa and Vinnie Savarese, holding 1-year-old twins Alexa Rose (left) and Samantha Danielle, with their maternal grandmother, Elaine Ingrisano (top left), and honorary grandparents, Diane and Paul Gianadda (top center and right)

would never have been born.

Until she was 28, Lisa had no reason to dwell on the health of her heart. But in December 1994, nearly a week after she brought newborn Nikki-Taylor home from

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the hospital, she became inexplicably sick. She reported her symptoms—high fever, chills, sore throat, congestion—to her doctor, but she was told that the flu was going around and to wait it out. And, indeed, Lisa was better within a week. A month later, though, she woke in the middle of the night gasping for air: “I felt like I couldn’t breathe—like I needed to go to the window for air.”

“I could see from her lab tests that all her organs were failing,” says her mother. “She was dying”

She chalked it up to the exhaustion of caring for a newborn and toddler, but her mother, Elaine Ingrisano, insisted she see her doctor.

Lisa’s internist detected a heart murmur and immediately sent her to a cardiologist. Even so, Lisa didn’t panic. “Many people have heart murmurs,” she thought then. “And besides, I’m only 28.” But an echocardiogram revealed the shocking news that Lisa was suffering from dilated cardiomyopathy, a life-threatening condition in which the heart is weakened and enlarged. It can have many different causes, including certain viruses, congenital anomalies and even pregnancy itself, but Lisa’s blood tests suggested that the “flu” she’d had a month earlier was actually a different virus she’d picked up in the hospital during Nikki-Taylor’s birth. It wasn’t a definitive diagnosis but it seemed the most likely explanation for why a healthy young mother would suddenly find herself with a condition that, doctors told her, would ultimately necessitate a heart transplant.

After a brief bout of self-pity (“I kept saying, ‘Why me? I’m so young,

I’ve got kids’”), Lisa regained her natural optimism. Medication soon had her feeling fine, and a surgically implanted internal defibrillator protected her from any potentially fatal arrhythmias by delivering an electric shock that would restore normal rhythms. Although doctors warned that eventually these treatments would prove insufficient to keep her condition in

check, Lisa never truly believed she’d need a transplant. “I just didn’t think it would happen,” she says.

There were plenty of health scares in the years that followed. Whenever Joe or Nikki-Taylor caught a bug, Lisa got sick, too—only her illness always lasted longer than theirs and invariably caused her heart function to diminish. Then it would be back to the hospital again for various tests to check her heart function. To add to the stress, Lisa’s marriage failed.

Then, on Memorial Day 1999, while Joe and Nikki-Taylor were at a barbecue with their dad, symptoms of full-blown heart failure reappeared. Suddenly Lisa couldn’t breathe. She called her mother, who sped her to a hospital in a nearby suburb. Doctors there sent her by ambulance to Mount Sinai Hospital, in New York City, 30 miles away, where a cardiac catheterization revealed that her heart was barely able to circulate her blood. Lisa was admitted to cardiac intensive care and told she couldn’t leave until after a healthy heart became available for transplantation.

Some patients wait months for an

organ transplant; others die waiting. But in one respect Lisa was lucky: Her blood type—AB positive—meant she could receive a heart from someone of any blood type, as long as it could reach her within four hours (the longest a heart can be outside a body) and the donor weighed within 100 pounds of what she did.

Even so, the wait seemed interminable. As nearly three weeks went by, Lisa grew weaker and weaker. A medical technologist at the time, Ingrisano understood how sick her daughter really was. “I could tell from her lab tests that all her organs were failing, not just her heart,” says Ingrisano. “She was dying.”

When Lisa developed pneumonia, her chances of survival plummeted. Then, one Saturday evening, as the family sat around her bed, a smiling nurse walked in and said, “Lisa, we have a heart for you.”

Some 400 miles away, in Buffalo, New York, another family gathered around another hospital bed. Just hours earlier Paul and Diane Gianadda, along with two of their children and more than a dozen other family members, had come together to say good-bye to their eldest son, Daniel.

That gorgeous summer evening should have been one of the proudest of their lives: the day their firstborn graduated from high school. In fact, Diane and Paul had been buying college supplies—Daniel was set to enroll in the honors program at the State University of New York at Buffalo—when they got the telephone call that every parent dreads: Daniel’s car had hit a tree, their younger son told them, and the boy was being airlifted to the Erie County Medical Center, a local trauma facility.

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At first Diane didn't understand how serious the accident was. Although very little is known, even now, about what happened, Daniel was only blocks from home at 6 in the evening—broad daylight. Moreover, he wasn't the kind of teen parents worry about: A straight-A student and passionate baseball player, he was someone teachers relied on to set an example for classmates. Even after hearing how grave Daniel's injuries were, Diane says, "It didn't occur to me that we could lose him—I just wanted to get him well."

Eleven years earlier, Paul, a contractor, had been rushed to the same trauma unit after suffering a major head injury at a job site when a concrete slab collapsed on him. Doctors had told Diane that Paul might never walk again, but miraculously, he made a full recovery. So when doctors gave them discouraging news about Daniel, Paul took inspiration from his own history. He told the doctors, "If there's any chance that surgery could relieve the pressure in his brain and he could come out of it, we want to take it." But by noon the following day it was clear the surgery had not been successful; Daniel had no brain activity.

Earlier in the evening Diane had noticed a sign about organ donation and, as she struggled to absorb the news about Daniel, broached the idea to her husband. Paul didn't hesitate. "How could you not want to keep some part

of your child still alive?" he asks.

For Diane, the decision was simple for a different reason: Daniel was someone who helped struggling kids with their schoolwork and volunteered to read bedtime stories to his little sister. She was pretty sure he'd never heard of organ donation, but was sure he would have approved. "He's that kind of kid," she says, not noticing she's speaking in the present tense.

Back in New York City, Lisa Savarese was panicking. "They won't let you have surgery with a simple cold, so I wasn't letting anyone take out my heart while I had pneumonia." That's when it hit her that she might not see her children again.

"You can't wait any longer," said Alan Gass, M.D., then the medical director of the transplant program at Mount Sinai and now director of cardiac failure and transplant at Westchester Medical Center, in Valhalla,



For Paul and Diane Gianadda (left, with a photo of son Daniel), the heart-shaped hemangioma on Samantha Danielle's neck (above) is a sign their son lives on

New York. The diseased heart that the surgeon removed during the four-hour surgery was severely enlarged.

Her mother could see the difference even before Lisa woke up. "Her coloring was so rosy," says Ingrisano. "It was beautiful to see color in her face again!"

Even with a strong heart, though, Lisa's recovery was long. In the first year after transplant, the risk of rejection—when the immune system recognizes a donated organ as alien and attacks it—is especially high, and Lisa was hospitalized several times to receive antirejection medications, which increase the risk of infections and certain kinds of cancer. Still, Lisa eventually began to thrive after her transplant. Soon her heart was functioning more effectively than most healthy people's, enabling her to care for Joe and Nikki-Taylor and, eventually, to fall in love with family friend Vinnie Savarese.

Yet even as she carried on with her own life, Lisa never forgot the boy who had lost his. (She knew only that her donor was an 18-year-old male.) "I thought about him when I woke up from the surgery, CONTINUED

and I've thought about him every day since," she says. On the first anniversary of the transplant she sent his family—about whom she'd been told no details—a letter through the hospital's transplant coordinator. "I told them I could never thank them enough for what they did."

The Gianaddas didn't respond, but the transplant coordinator had already

respects), Diane took a leave of absence from her job as a teacher's aide to comfort her devastated children, Tom, John and Sarah. Lisa's letters were hard to read. "We were happy for her, but they reminded us of our loss," says Diane. But the third letter made Lisa's children so real that the Gianaddas finally felt ready to reply.

"After you lose a loved one, espe-

grateful in return. "Every time I see Lisa, I picture Daniel sitting with her," says Paul.

Somehow the two families felt immediately that they belonged together. "I have never felt so close to anyone so quickly," Lisa says. That July the Gianaddas were honored guests at Lisa and Vinnie's wedding. At the reception, the couple presented a slide show of pictures of them growing up, pictures of the important people in their lives. "At the end, there was a picture of Daniel," Lisa says, "and a slide thanking Paul and Diane for giving me my life."

"There wasn't a dry eye at the reception," Paul says.

After the wedding the Savarese and the Gianaddas settled into thinking of each other as extended family, talking weekly, visiting when they could. So it was natural that when Lisa became pregnant Diane was among the first to hear.

While pregnancy after heart transplant is not unheard of, it is rare because it's dangerous: Pregnancy strains the organs and immunosuppressant drugs carry a serious risk of infection. There have been only 39 reported cases of heart recipients who have become pregnant, according to the National Transplantation Pregnancy Registry at Temple University School of Medicine. Lisa's case was complicated by the fact that her heart first failed around the time of Nikki-Taylor's birth; although her doctors believed her cardiomyopathy resulted from a viral infection, there was still a chance that pregnancy had caused it.

But Lisa, who wanted more children, was undaunted. "I'm extremely careful about my

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"I have never felt so close to anyone so quickly," says Lisa about meeting her donor's parents

warned Lisa not to expect an answer. Still, on the surgery's second anniversary, Lisa wrote again, explaining she hoped to meet them someday to thank them in person for giving her the gift of a future. By the third anniversary Lisa had begun to worry that perhaps her letters served only as a painful reminder of what they'd lost. She decided to skip the ritual that year.

When Lisa mentioned this decision to her mom at Christmas, however, Ingrisano was adamant. "You have to let them know you're still alive," she said. So in January 2003, Lisa wrote one more letter. This time, she enclosed photos of herself with Vinnie, with Nikki-Taylor and Joe, with her mother and grandmother—a dozen joyful pictures of a family that would still be grieving if the Gianaddas had not made their fateful decision.

"Seeing her children is what did it for me," remembers Diane. "I knew then it was time to write."

The years following Daniel's death were not easy for the Gianaddas. After the visitation and funeral (where nearly 3,000 mourners paid their

especially a child, there is a black hole in your being that never seems able to be filled again," Diane wrote. "When we hear from you, it helps to ease the emptiness." She ended the letter, "Your children are beautiful. I am very thankful that God chose you to live on and share your life and your love with them."

The Gianaddas made plans to meet Lisa and her family on Memorial Day that year, during Fleet Week, when they would all be coming to the New York area to see their son Tom, who was in the Navy. When Joe looked out the window and announced that the Gianaddas were pulling up, Lisa's heart raced. Diane remembers feeling awkward: What should she say? But when they met, the two women hugged tight, reluctant to let go. Then Lisa held Diane's hand to her heart, so she could feel it beating.

Over dinner at a nearby Italian restaurant Lisa surprised the Gianaddas with gifts, including a heart-shaped diamond pendant for Diane and a watch for Paul, engraved THANK YOU FOR GIVING ME THE GIFT OF TIME.

The Gianaddas were moved and

medicines and my checkups, but I don't live my life scared," she says. So after a battery of tests showed that she was healthy, Dr. Gass supported her decision.

The Gianaddas were concerned about Lisa's health, but they never questioned her decision, never once wondered if she ought to be putting such a strain on Daniel's heart. But that first pregnancy, and the next, ended in miscarriage.

Then, in fall 2005, an ultrasound during Lisa's third posttransplant pregnancy revealed a big surprise: two tiny embryos, each with a strongly beating heart. Lisa and Vinnie stared at the screen in disbelief, but once they recovered both were thrilled.

Lisa's doctors, on the other hand, were anything but. Carrying twins doubles the already great strain that pregnancy places on the heart, and it significantly increases the risk of preeclampsia, a life-threatening condition that can cause seizures or stroke and can be cured only by delivery, even if the babies are too premature to survive. The National Transplantation

in the pregnancy. "We thought we could minimize the risks by limiting the amount of work her heart had to do," Dr. Stone explains.

Lisa and Vinnie were tormented, shocked at the risks but horrified at the idea of ending the life of a baby they longed for. "I was against the reduction," says Vinnie, "but if it had come down to one child and one wife, or two children and no wife, for me it would've been one child. But it was Lisa's decision, and she was dead set against the reduction."

Lisa says she just had a good feeling about her prospects: "I kept saying to myself, 'God is not going to take this from me.'"

Lisa's confidence notwithstanding, Vinnie worried, Ingrisano worried, the Gianaddas worried. ("We prayed for Lisa every day," says Diane.) Even little Nikki-Taylor, then 11, worried. "She was always crying," says Lisa. "She knew I'd gotten sick right after she was born and thought it would happen again. She really thought I was going to die."

But as Lisa predicted, everything

Daniel Gianadda had been an athlete, and Dr. Stone attributes the unexpected happy ending in part to the robust heart Lisa received from him, and in part to Lisa's own positive attitude. "She proved us wrong," says Dr. Stone.

The Gianaddas feel almost like grandparents to the twins. Lisa calls at least once a week with updates and sends e-mails and pictures every chance she gets. When Lisa, Vinnie and the twins came for a visit at Christmastime, the Gianaddas invited all their neighbors to meet "our girls." And last May Diane got a Mother's Day card from the Savarese children; it was addressed to "Grandma Diane Gianadda."

There's one more thing that makes Paul and Diane feel even more deeply connected to the Savarese: On the back of Samantha Danielle's neck is a small strawberry-colored birthmark called a hemangioma. It wasn't there at birth but developed gradually during Samantha Danielle's first two weeks of life. "When I first noticed it, it was raised, like a little red bump," says Lisa. "It got bigger and bigger, and within a week or so, it developed into a shape." Everyone who sees it immediately identifies it as a small, perfectly shaped image of a heart.

"I don't believe in coincidence," says Diane. "I mean, why a heart? And why on the twin who's named for Daniel and not the other? There's a message there."

"It's another sign that our son lives on," agrees Paul.

It's a sign, too, of the bond these families share. "I love them—they're my family," Lisa says simply. "How can I explain it? It's like it was just meant to be." **CONTINUED ON PAGE 118**

Lisa's little girl cried throughout her mother's pregnancy: "She thought I was going to die"

Pregnancy Registry had never recorded a twin pregnancy in a heart recipient, so Lisa's outcome was impossible to guess, but she could have ended up losing her life, her babies, or both.

Joanne Stone, M.D., Lisa's high-risk obstetrician at Mount Sinai, suggested multi-fetal pregnancy reduction, a medical procedure that terminates one of the embryos early

turned out fine. She did develop preeclampsia, but it came on slowly enough for Dr. Stone to give her steroid injections to hasten the babies' lung development. When they were born at 33 weeks, both were breathing on their own. Samantha Danielle was four pounds, 12 ounces, and Alexa Rose was an even four pounds (typical birth weights for twins); both were healthy.