

# Liver Donor's Family, Recipient to Meet

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Posted: 2008-07-07 01:13:41

Filed Under: [Nation News](#)

PITTSBURGH (July 6) - They were precocious toddlers, both blond-haired and blue-eyed, separated by a thousand miles between Miami and a small Kentucky town.

## Face to Face, 25 Years Later



*Alan Diaz, AP*

Trine Engebretsen received an extremely rare liver transplant after she was born with a genetic disorder. Now, a quarter century later, the aspiring doctor soon will have the chance to thank the family whose tragic loss ultimately saved her life.

The two girls would never meet, but would be brought together through unthinkable tragedy: Trine Engebretsen was born with a genetic disorder that would require what at the time was an extremely rare liver transplant, and Amanda DeLapp would die at just 18 months after being stricken with a brain tumor.

In an operation in Pittsburgh in 1984, Amanda's family donated their daughter's liver to Trine, making her one of the nation's youngest patients ever to receive a liver transplant.

For years, each family would try to contact the other. Trine's family sent a picture of their

daughter dressed for Christmas to the DeLapp family, a picture that still sits on the bedroom dresser of Alisha DeLapp, Amanda's mother. That correspondence was followed by years of miscommunication, with each family mistakenly thinking the other didn't want any contact.

But Amanda's younger sister, born after her death, never gave up hope of one day meeting the girl who received her sister's liver. Keisha DeLapp had found Trine on the Internet years ago, and read about her participation as a swimmer in the U.S. Transplant Games. She read about Trine's wonderful health, including her complete independence from drugs that prevent organ rejection.

Like other twentysomethings, Keisha also kept a MySpace page, with a simple quote at the top: "Faith is not simply believing that God can ... It is knowing that He will."

Earlier this year, Keisha looked for Trine online again, found her on MySpace and sent her a greeting:

"Hi. I'm Keisha DeLapp, Amanda DeLapp's sister. Me and my family would love to have contact with you if you would like to. Let me know."

This month, the U.S. Transplant Games will be held for the first time in Pittsburgh, one of the pioneering centers for transplants in the country, and 25 years after the operation that forever connected the Engebretsen and DeLapp families.

At the games, these two families will look each other in the eyes for the first time, exchanging hellos, hugs and memories of the event that changed both their lives.

Amanda was Alisha DeLapp's first child, born in 1981. The little girl known as Mandy to her family was healthy and happy, even walking by the time she was 8 months old, her mother recalls.

A year later, everything changed. Amanda was hospitalized because she was vomiting and had pneumonia-like symptoms. Her parents rushed her to the hospital closest to their Mayfield, Ky., home, but doctors were unable to figure out what was wrong. As her condition deteriorated, doctors sent Amanda to a hospital in Nashville, about two hours away.

Doctors there found the problem, telling Amanda's anxious parents their daughter had a

brain tumor and was going to die. Amanda DeLapp was 18 months old.

A nurse at the hospital asked the couple if they would consider donating Amanda's organs.

"To me, at that time, it had to be God helping us to decide," Alisha DeLapp remembers. "I can look back at that now and know it was the hardest decision I ever had to make."

Alisha and her husband returned home. On TV, they saw on the news that a little girl named Trine had received a liver transplant. Alisha remembered the little girl; she had seen Trine and her mom, Mary Ann Lunde, on the Phil Donahue show appealing for help. They had also made other national TV appearances.

The DeLapps knew immediately that their daughter's liver had saved Trine's life. (They later learned that Amanda's kidneys were donated to a man in his 20s.)

Transplants were rare at the time, and in a matter of hours the local news channels were calling the DeLapps for comment. They agreed to an interview with a local TV station, which was broadcast on the "Today" show.

The DeLapps' were interviewed along with Trine's family. They didn't speak directly to each other, but it was the closest the families would come to it for years.

Trine Engebretsen, now 26, doesn't remember much about her lifesaving liver transplant when she was 2½ years old.

She had been born with a genetic disorder called alpha-1 antitrypsin deficiency, which resulted in her body not producing enough of a key enzyme in the liver.

In addition to the family's appeals for help on TV, her father, a Norwegian citizen, appealed to the Norwegian government, which agreed to pay for Trine's surgery. He was Norway's youngest passenger ship captain, and was lost at sea in a hurricane when Trine was 13.

When Trine arrived at Children's Hospital of Pittsburgh for the transplant, doctors estimated she had less than 24 hours to live.

She was one of several children who had transplants at the Pittsburgh hospital in 1983

and 1984, remembers pioneering transplant surgeon Dr. Thomas Starzl, who performed her operation. The patients were known as "Reagan children," because then-President Reagan had been using his Saturday radio addresses to drum up public interest in transplantation.

"At the beginning of the 1980s, the only place in the U.S. that was doing these was here in Pittsburgh," Starzl said.

Starzl remembers Trine and over the years says he has met several donor families.

"I was profoundly and still am profoundly grateful to them, particularly in those days because it wasn't common (to donate organs). It required a lot of social conscience," Starzl said.

Over the years, Trine's family tried to contact the DeLapp family. She knew the family lived in Kentucky, but says letters her mother sent to an address for Amanda's grandparents were returned, unopened.

Several years ago, Trine wrote a thank you note to the DeLapps for her transplant and gave it to the organ-procurement organization for Kentucky hoping they could pass it along to the family. The note never made it to them.

Meanwhile, she immersed herself in transplant-related endeavors.

"I very much feel that it's important and also I like to give back. I don't feel like I'm under an obligation. I want to give back," Trine said.

She first attended the U.S. Transplant Games in 1992, and has attended most of the games since then. She has participated in swimming, running and even signed up for the shot put this year.

She met her fiance, Ryan Labbe, in an online forum about organ transplants. He moved from New England to Miami to be with her, and received his own liver transplant earlier this year.

Trine has been off immunosuppressant medications for 11 years, something that's becoming more common among transplant recipients. She is applying for medical school, in hopes of studying something transplant-related, and works for the Life Alliance Organ

Recovery Agency in Florida.

On a Friday night at her office, around 6 p.m., her Blackberry went off. It was a friend request from her MySpace page.

It was from 23-year-old Keisha DeLapp.

"I almost fell off my chair," Trine says.

Alisha DeLapp, now 48, had gone on to have Keisha and a son before she and her husband divorced. She followed Trine's progress through online stories from the various U.S. Transplant Games she competed in over the years. She kept the picture of Trine as a child in her Christmas dress — eerily, it was the same dress Amanda had worn in a Christmas snapshot — and hoped one day to be able to update it with a more recent photo.

"I know it's not my daughter, but it's just as special knowing that my daughter saved her life," Alisha DeLapp said. "I'm proud of her, with the things that she's chosen to do with her life. It's so impressive to me."

The two families have been communicating via e-mail since Keisha and Trine made contact earlier this year. They've talked about the many years they tried to connect, and how thankful they are for each other — each in their own ways.

"I've waited 24 years to be able to say thank you," Trine says from her home in Florida.

When the transplant games commence on July 11, the three will meet for the first time in downtown Pittsburgh, just miles from where Trine's surgery took place. Starzl will also be there to greet them. The women will give thanks for each other through hellos and hugs, and probably some tears.

"I never got to know my sister. I never got to meet her or anything. By no means is Trine my sister, but that's kind of like a part of her," Keisha says. "This whole experience, I'm just glad that it happened."

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2008-07-06 16:03:52

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