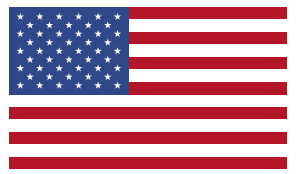




'THAT'S MY BABY!'

LITTLE JASMINE FOUND SAFE IN WEST VIRGINIA AFTER BEING ABDUCTED ON CHRISTMAS EVE. PAGES 2-3

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FRIDAY, DECEMBER 28, 2001

Late Sports Final

THE GIFT

A TRANSPLANT JOURNEY

Third of four parts

'You need to get here ... Something's wrong.'

By Chris Fusco | Staff Reporter

My friend Mark Mucha spent New Year's Eve laughing with his wife and friends during an impromptu gathering at his town house in Orland Park. His 8-month-old son, Jacob, slept upstairs.

I celebrated the new year in the maternity wing at Central DuPage Hospital holding Benjamin, my newborn son.

Our transplant surgeries less than a month earlier, on Dec. 12, 2000, seemed light-years away.

Mark's body was accepting the liver I had given him, and we both would spend January at home recovering with our sons.

Or so we thought.

Story continues on Pages 10-13

Readers react to The Gift: A Transplant Journey.

LETTERS TO THE EDITOR, PAGE 40.



RICHARD A. CHAPMAN/SUN-TIMES

Mark Mucha spent almost all of March fighting for his life behind these doors.

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THE GIFT A TRANSPLANT JOURNEY

'The liver is totally dead. They're looking for another one right now.'

Mark wasn't feeling well when he arrived for a checkup at the University of Illinois at Chicago Medical Center on New Year's Day. An X-ray showed that bile, the liquid that the liver produces to aid digestion, was seeping out of the ducts that connected the liver with the rest of his digestive system.

Bile leaks are a common complication among live-liver transplant recipients, and Mark ran a higher risk because the ducts that came with my liver were unusually thin.

What was surprising, though, was that infected fluid was building up so quickly that Mark barely could breathe. Our transplant surgeon, Dr. Enrico Benedetti, rushed him into surgery.

Benedetti drained the fluid and cleaned out the infected area. He inserted a chest tube to drain any more fluid that might build up.

Nine days later, Mark had more surgery—this time to put in two chest tubes and repair a hole in his chest wall. The operation was excruciating. Surgeons had to separate his rib cage so they could work on his right lung.

Despite the pain, Mark never complained, especially not to me, because I had begun having complications of my own.

Early Jan. 8, I stiffened up at home to the point that I couldn't walk. My father-in-law drove me to UIC around 1 a.m., where Demerol shots helped me rest.

Benedetti arrived and said not to worry. I had the flu, and it had made me extremely achy because my body also was fighting an infection around my incision. Benedetti had a resident cut out my incision's core to solve the problem, leaving an inch-long, half-inch deep hole in my gut.

I felt better almost instantly, but I needed to stay home for the next three weeks as home-health nurses kept the wound clean. It closed up just after that.

What I was going through at home was nothing compared to Mark.

Treating his bile leak was difficult, Benedetti said, because Mark was taking drugs that suppressed his immune system so he wouldn't reject the new liver. At the same time, those anti-rejection medicines made him more susceptible to infection.

Benedetti proposed a temporary fix as Mark's third-straight week at UIC began. It entailed surgically inserting a mushroom-shaped drain that would collect bile and other infected fluids, route them through a chest tube and into a bag outside his body.

The operation on Jan. 18 was designed to give Mark's incisions time to heal. When Mark felt healthy enough, Benedetti planned to perform another surgery that he hoped would plug the bile leak for good.

Mark went home the day after sur-



Mark + Ben

Me + Jake - 1-28-01

Mark met Ben for the first time. He loved holding my son, partly because he was excited to see him and partly because Jake had grown too big for him to hold right now.

gery. He returned to the hospital for a two-night stay the next week so doctors could adjust the drain.

Home-health nurses were at Mark's house at least twice a day, cleaning out his chest wound and changing the bag—which Mark found painful and gruesome, but which his wife, Kelly, later mastered.

■ ■ ■

Benjamin, my wife, Jennifer, and I visited Mark, Kelly and Jacob at their home on Jan. 28.

Mark met Ben for the first time. He loved holding my son, partly because he was excited to see him and partly because Jake had grown too big for him to hold right now.

I'd be back at work in three days, and I hoped Mark would be contemplating his own return. But within five minutes at his house, it became clear that his pain from the surgeries was as bad as ever, and it was starting to take a toll.

We drove to Walgreens to put in one of his prescription orders, then picked up a pizza for dinner. Mark grimaced when he got in and out of the car.

He ran through a list of problems on our short trip. His son was having trou-

ble recognizing him because he had spent so much time in the hospital. He couldn't sleep well because he was in so much pain. He couldn't believe how much work Kelly had to do to clean his wound and take care of Jake.

I tried to reassure him that everything would be OK, that he just needed to get through this next surgery.

"I hope so," he said.

He popped two Vicodin back home, and his mood improved.

We ate and talked around the kitchen table like we used to before Mark's cancer. I held Ben.

For a moment, everything was perfect.

■ ■ ■

Mark spent virtually all of February at home. His incisions were healing, his mood was improving, he was eating normally and, most of all, his liver was healthy.

He checked back in to the hospital Feb. 26 for what everyone hoped would be his last operation—redoing the connection between the bile ducts and his digestive tract. The four-hour surgery took place the next day.

Less than 24 hours after the operation, his temperature, pulse and blood

THE STORY SO FAR

Mark Mucha is diagnosed with liver cancer, and his friends and family answer the call to be his liver donor. His friend, Sun-Times reporter Chris Fusco, is chosen. Things look good after the transplant. Complications develop, but everyone stays hopeful.

pressure were normal. A resident reported he was "doing well" with "minimal jaundice."

Kelly e-mailed Mark's friends and family with the good news.

"We have achieved the best outcome possible," she wrote. "God has heard our prayers and answered them."

■ ■ ■

Mark called Kelly at 5:50 a.m. on Friday, March 2. He was out of breath.

"Kel, you need to get here," he said. "They're taking me in to surgery. Something's wrong."

Kelly got in her car and called her parents, Mark's parents and me. She didn't sound overly concerned, but I decided to go to the hospital anyway.



RICHARD A. CHAPMAN / SUN-TIMES

Mark's slide was difficult for even Benedetti to comprehend. As of 11 a.m. Thursday, his temperature was 98.7, and his blood pressure and other vital signs were normal.

Kelly was in the waiting room with her mom, Carole Frank; Mark's mom, Alice Mucha; and his sister, Sandi. Kelly didn't let on to the gravity of the situation, so our conversation focused on how Jake was learning to be every bit as stubborn as his old man.

Benedetti motioned Kelly out just after 9 a.m.

"It's not good, Kelly," he told her.

"Is he going to die?" she asked.

"Maybe," he said.

She came back to the waiting room crying.

"The liver is totally dead," she said, standing in the doorway. "They're looking for another one right now. . . . If they don't find one within 72 hours, he's going to die."

Kelly's legs gave out. She fell into her mother's arms.

Alice and Sandi, both crying, left to call Mark's dad, Ed, and brother, Matt.

Shocked and confused, I called my wife, parents and friends, many of

whom were at UIC within an hour.

■ ■ ■

Mark's slide was difficult for even Benedetti to comprehend. As of 11 a.m. Thursday, his temperature was 98.7, and his blood pressure and other vital signs were normal.

The liver didn't show signs of failure until Thursday night, said Benedetti, who left home to come to the hospital. Within hours, "he was pretty much dying under our eyes," he said.

The liver looked gray and dead when Benedetti opened Mark on Friday morning. An inexplicable clot had formed in his hepatic artery, which brings blood to the organ.

"Usually in the first 10 days [after transplant] if you have this, it can be fatal," Benedetti said. "When you have it three months later, it should not kill the liver. But in this case it did."

The hospital listed Mark as a priority

candidate for a cadaver liver.

Almost miraculously, one from a man in his 50s was found before noon.

Suddenly, the despair turned to hope. A half dozen people went to donate blood for Mark's surgery.

Kelly let me in to Mark's room shortly before the doctors wheeled him off at 3:45 p.m. His skin was a horrifying yellow, and a greasy sweat drenched his hair. A mess of tubes, intravenous lines and monitors surrounded him.

Mark was too weak to talk and barely could move, but you could tell he knew.

I took my buddy's hand and told him everybody outside was praying for him.

He nodded.

■ ■ ■

With Mark in surgery, the rest of us ate hamburgers and did our best to keep Kelly from losing it. The hospital normally reserved the hospitality room in which we waited for doctors. It would become Kelly's sec-

ond home during the next month.

Mark didn't come back up to surgical intensive care until 1:15 a.m. He breathed on a ventilator and was on drugs to keep him unconscious and paralyzed. He was still bleeding internally and would go through 44 units of blood—one unit being the equivalent of what a person donates in a normal sitting.

Less than 24 hours after surgery, doctors took him back to the operating room, pulled back the mesh that was keeping his innards in place and sealed his internal wounds.

With the bleeding under control, his weight ballooned to what looked like 250 pounds Sunday—most of it water weight. Just when Benedetti talked about putting Mark on kidney dialysis, his urine output skyrocketed.

Slowly, his body began to accept the new liver. But on Tuesday, March 6,

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THE GIFT A TRANSPLANT JOURNEY

Continued from Page 11

another setback: Mark was running a fever, a sign of a possible infection. It subsided the next day.

On March 8, doctors stitched up Mark's incision—a sign that they hoped they wouldn't have to operate on him again. The next goal was to get him out of his drug-induced haze and breathing on his own.

■ ■ ■

Every morning after Mark's second transplant, Kelly awoke on the sofa bed in the hospitality room, showered, walked down the hall and around the corner through the double doors into surgical intensive care. Mark was in the second room on the right.

She put on a gown and rubber gloves and stood next to him as his ventilator hummed. She kissed him, talked to him, rubbed his hair, read him football books and welcomed visitors, making sure they also donned gowns and gloves to reduce the risk of infection.

"C'mon, you stubborn Polack. Wake up," she told him repeatedly. "Dr. Benedetti says your liver is doing well. Keep fighting. You're going to be OK."

It was hard to believe this was the same girl I met 12 years ago before she fell in love with the unresponsive man in the hospital bed.

Now, a poster-sized picture of Jake hung on the wall. A picture of Ben with the message "Uncle Mark, Get Well Soon" hung above it.

Kelly would point to them. Mark wouldn't open his eyes.

But she stayed optimistic.

She thanked everyone for their prayers in an e-mail March 12:

"Every morning I wake up, I count on it being a little better day than the last," she wrote. "I am here every day working him like a dog. He will probably file a restraining order against me the day after he wakes up."

"Don't worry, he is a fighter. . . . He is going to make a nice recovery. He just needs some time."

Five days later, on March 17, Mark was wide awake for the first time. The ventilator came out of his mouth.

■ ■ ■

The next day, Kelly stopped Jennifer and me before we went in to Mark's room.

"Chris, make sure to tell him you're fine. He's a little bit confused and thinks because he's in the hospital and had problems, you're sick, too," she said.

Indeed, Mark looked at me like I had risen from the dead when he saw me walk in. "F-f-f-usco," he said, his voice scratchy from being on the ventilator for so long.

"I'm OK. You're the one that's making everybody scared," I told him. "How are you?"

"I'm good," he said. "They've been taking good care of me here. . . . My wife's been taking good care of me."

He smiled at Kelly.

"Who are these two guys?" I asked Mark, pointing at the pictures of our sons.

"That's Jacob," he said right away.

"And what about this other guy?"

"That's your son."

"What's his name?"

"Don't tell me. It begins with a B. B. B. . . . oh, I don't know. Bartholomew."

"No. How about Benjamin?"

"Benjamin, yes Benjamin. He's a



RICHARD A. CHAPMAN / SUN-TIMES

Every morning after Mark's second transplant, Kelly awoke on the sofa bed in the hospitality room, showered, walked down the hall and around the corner through the double doors into Mark's room.

good-looking kid."

"They're both good-looking kids, just like their dads."

Kelly and Jennifer rolled their eyes. During the next two hours, Mark had us in stitches. He was excited that our friend from high school, Erik Kantz, finally had proposed to his longtime girlfriend, Chris Dorgan.

"It's about time," Mark said.

Later, the subject of unconventional songs came up, so Mark entertained us with a few verses of "Muskrat Love."

He also rolled out a childhood staple—the song that the Ewoks sing at the conclusion of "Return of the Jedi."

Toward the end of our visit, I helped the nurses move Mark into a large chair. While his personality was back, it was clear that his strength wasn't. Besides the memory loss and overall weakness, he also was experiencing facial tics and occasional hallucinations, most likely from all the drugs that were in his system.

Still, everybody was optimistic.

"If we can just have him sitting up on his own for Jake's birthday," said Mark's mom, Alice.

■ ■ ■

Two days later, Dr. Benedetti was on the phone with the nurses in surgical intensive care around 7 a.m. A nurse told him that Mark looked the best she'd ever seen him.

He sat up in a chair that morning and was talking to a resident. His liver-function tests were approaching normal levels.

Benedetti started talking with another nurse about another patient when he heard a yell, "Mark Mucha arrested. Mark Mucha arrested."

Mark had gone into respiratory arrest, a condition in which his lungs stopped working and caused his heart to stop. Though Benedetti doesn't know exactly what caused it, he believes a blood clot in Mark's leg that he had been treating might have slipped through a filter and migrated to his lungs, cutting off blood flow to them.

Doctors and nurses revived Mark within seconds, but his short time under further damaged his already overworked body.

Unable to breathe normally, he went back on the ventilator. And despite breathing and feeding tubes going down his throat, he kept trying to talk and sit up. The doctors put him in restraints.

At this point, Mark's lungs—not his liver—were the doctors' utmost concern. If they didn't respond to treatment from the ventilator, they'd stop bringing oxygen to Mark's blood.

Without that oxygen, Mark would die.

Mark knew exactly what was going on. When the nurses asked if he was in pain, he'd nod and grimace. His only apparent joy was having his mouth swabbed with a lemon-flavored sponge.

I visited Mark on Thursday, March 22. When Kelly left the room for a second, he began mouthing words. I couldn't make them out.

When I told him to stop, he kept going. Finally, I clenched my jaw and looked him straight in the eye.

"I know you're in hell, and I know it's driving you crazy," I said. "But listen to me, you've got to keep fighting. There's no way I'm giving up on you."

Mark stopped moving and just looked at me. Kelly came back in.

■ ■ ■

Hoping to put him in a better mood, Kelly's parents bought Mark a TV/VCR for his room so he could watch tapes of his son.

It never made it out of the box.

On Friday, March 23, doctors made the decision to again give Mark drugs to paralyze him. His fidgeting and attempts to talk were keeping the ventilator from doing its job. The best thing for him was rest, they said.

That night, Kelly slept outside the hospital for only the second time since Mark's second transplant surgery. The next morning, Benedetti told Kelly it didn't make sense for her to sit next to him at the hospital.

She came out to our house to spend the day with Jennifer. A page from the hospital interrupted their plans.

Mark's blood pressure suddenly dropped, and his lungs weren't improving.

Jen and Kelly drove to the hospital, where they later were met by several family members and friends. Until the others arrived, they sat in a nursing office, held each other's hands and



RICHARD A. CHAPMAN / SUN-TIMES

I waited with Mark's mom, dad, brother and sister in a nursing office across from his room, swapping stories about Mark with them for several hours. Though we knew he was fighting for his life, we still believed he'd bounce back.

prayed for at least two hours straight. There were too many doctors and nurses going in and out of Mark's room for them to be with him.

I stopped at UIC briefly before heading to work at 5 p.m.

My editor let me out early, around 11:30 p.m., so I could go back to UIC. Jennifer, our friend Erik and his fiancée were with Kelly.

I waited with Mark's mom, dad, brother and sister in a nursing office across from his room, swapping stories about Mark with them for several hours. Though we knew he was fighting for his life, we still believed he'd bounce back.

At some point, I wandered in to Kelly's hospitality room to get some sleep on the floor. Kelly's mom was sleeping on the couch.

Around 6 a.m., Kelly came in and turned on the lights.

"He's not oxygenating any more," she said.

She began to cry.

"If they can't get him to oxygenate

within the next few hours, they want me to pull the plug."

Around 8:30 a.m., Benedetti and another of Mark's doctors, Luca Cicalese, came to the hospital.

For a second, there was a ray of hope—if Mark could stay stable for 24 hours, his body might respond.

Kelly walked out of the meeting determined.

"OK, Mucha, we're not giving up on you yet," she told him. "They want you to hang in there. Keep fighting."

Erik and Chris were sitting next to Mark with Kelly when Jennifer and I left.

We hadn't seen our baby in nearly 24 hours. We needed to get some sleep if we were going to be back at the hospital at night, so we went to my in-laws' house, where Ben was staying.

■ ■ ■

Our friend, Jon Harmening, paged me about four hours later as I slept in a family-room chair.

"You need to get back here," he told me.

"Why?" I responded.

"His blood pressure dropped again. Just get back here."

I got Jennifer out of bed, and we fought the traffic back to UIC.

When we got to the hospital, Kelly's brother Patrick told us Mark had died about 15 minutes earlier, at 3:05 p.m.

Mark's father, Ed, came down the hall. We hugged, and he thanked me.

"I wish I could have done more," I told him.

Jennifer and I walked in to Mark's room with Erik and Chris. Though his skin was black and blue, he looked better now that all the tubes, monitors, bags and IVs had been removed.

He appeared to be half-smiling.

We cried.

"Mark, I'm proud of you. Proud of how hard you fought," I said. "I didn't tell you that earlier because your wife was doing all the talking, and I know if I was in your position, I would have

COMING SUNDAY, PART FOUR

Looking for answers, trying to move on

A 28-year-old father's funeral, a controversy over live-donor liver transplants and an attempt to make sense of it all.

On the Web: Read previous parts of "The Gift: A Transplant Journey" online at www.suntimes.com.

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wanted it that way, too."

I could hear him laughing in my head. We packed up the hospital room and went to Mark's in-laws' house.

Jake was in the family room, his toys scattered on the floor. He smiled at us and kept on playing.