

Jessica Toscano's Story



We brought our adopted daughter Jessica home from Bayonne General Hospital in the spring of 1999. She was amazingly beautiful, and only a few days old. We were meant to be her parents; we knew that from the start. For 10 years, she thrived. At a young age, she had obvious athletic talent. She excelled at everything she tried and was very creative.

Then, one day before her tenth birthday, I noticed her eyes looked a little yellow. The doctor ran some blood tests, and said Jessica's liver was sick, it could be hepatitis or something she had eaten. Within a few days, her skin turned very jaundiced. She was admitted to Saint Peter's and tests were run overnight. The next morning we were taken to Children's Hospital of Philadelphia. She needed to be at a liver center, because she might need a transplant! Her liver was dying and they could not find the cause! They never found the cause, but it didn't matter, because you can't live without a liver. She was put on the top of the transplant list, with two weeks to live.

After the transplant, her father and I were reassured that most kids will do very well. The body adjusts to the liver gradually. Sometimes anti-rejection medications are not needed forever. We tried to be optimistic. She was discharged in a few weeks with 20 staples holding her belly together.

Unfortunately, it didn't go well. She turned out to be the child for whom nothing went smoothly. First she had several serious episodes of rejection in the first year. She then developed 'chronic rejection' that lasted almost 3 years. She became frail and sickly during that time, and faced several life-threatening situations. During this period of time she endured many medical procedures and admissions, and generally suffered greatly. Among other things, she fell way behind in school, developed osteoporosis

and fractured her spine and her hip, lost her prepubertal growth spurt (and her growth plates fused), had delayed puberty, and turned yellow again.

She finally stopped rejecting, and her liver damage healed. By the end of 8th grade, she started to gain weight again. During her freshman year, she felt perfectly healthy. All she had to do was take a lot of pills. .

Then in the fall of her sophomore year, we took her to St. Peter's again, with pain that was suspected to be appendicitis. Instead, the CAT scan showed a large pelvic abscess! Again, the cause was elusive, except for the fact that she was immune-suppressed and she was female. She was in horrible pain. The treatment was antibiotics and surgical drainage, and it turned into a month in the hospital. This time they said that the inflammation and antibiotics were starting to seriously harm her fragile kidneys. During the time of this second relapse, her kidneys completely failed. Due to all this, she ended up losing 30 lbs. and became very weak. She is now on dialysis, in physical therapy, on continuous antibiotics, and will need tube feedings for months. But Jessica is fighting back again.

She needs to gain at least 20 lbs. before she is strong enough to face an open surgery that will hopefully completely eradicate her infection for good. After that, we hope for a miraculous recovery of her kidneys. Or maybe she will need a kidney transplant this time. Another journey we may have ahead. Meanwhile we live in hospitals and/or hotels in Philadelphia. . The money will run out at some point, but all we think about now is getting our daughter back to the healthy, happy life she deserves.

She knows her life will not always be easy, but she believes she has a purpose; she believes she is meant to help others in the future who have gone through something similar. She says, if you haven't been there like me, you can never understand.

