

Simon's story -- the power of love in every life

By Sheryl Crosier

Simon Dominic Crosier was born on September 7, 2010, in St. Louis, Missouri. He was diagnosed with trisomy 18, and lived for three memorable months before passing away on Dec. 3, 2010. Despite his disabilities, Simon had a huge impact on all who came into contact with him.

Before Simon's arrival my husband, Scott, and I lost six children through miscarriage. With each loss the sting of pain was greater. After we lost our daughter Faith in September 2008, we rid our home of most of our baby items.

Losing a child is a pain so deep that is difficult for anyone to grasp. It can be like falling down a chasm that seems to have no bottom. The chasm is lined with thorn branches that scrape and pull at your skin when you remember what you have lost.

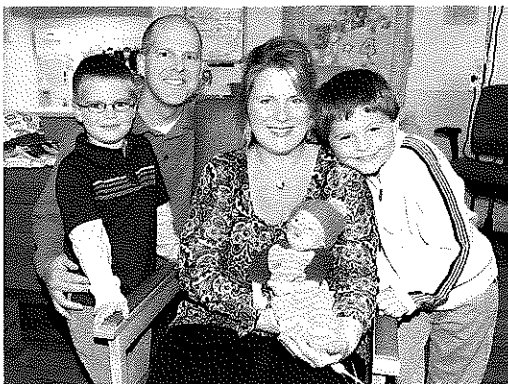
When we learned we were expecting in early 2010, Scott and I, along with our sons Samuel, at the time age 7, and Sean age 5, were filled with joy and yet terrified at the thought of losing another baby.

On the day of Simon's birth we embraced our son with sheer happiness, despite his cleft lip and clenched fists. Although doctors were concerned, our family felt only hope.

On day two of Simon's life the echocardiogram revealed that his heart was broken . . . and so was mine. My son had major heart defects that prevented the efficient oxygenation of his blood, resulting in pulmonary hypertension and severe apnea episodes during which he would stop breathing.

On Simon's third day of life, he was diagnosed with trisomy 18, also known as Edward's syndrome. This condition involves an extra chromosome in the sequence of 18 -- just as trisomy 21 affects the 21st chromosome for people with Down syndrome.

I will never forget when the Neonatologist walked into Simon's room and said, "The results are in. Simon has full trisomy 18.



Sheryl Crosier, holding little Simon, with husband Scott, and Simon's brothers Sean (left) and Samuel.

special needs kids are not worth the effort. Ninety percent of trisomy 18 babies have heart defects and 95 percent aren't brought to full term. Many are aborted when their conditions are revealed during prenatal testing. Only one in 6,000 comes into the world.

After Simon was diagnosed with trisomy 18, his care and treatment changed dramatically. We began to hear doctors say "Not for Simon" when aggressive treatment options were considered.

Struggling with the fragility of Simon's life was one thing,

Fighting the popular, pragmatic culture that measures human life in terms of dollars rather than dignity, is quite another. As St. Louisan Dr. Steve Cantrell, a parent of Ryan, a deceased trisomy 18 child, stated, "Our kids are not disposable and deserve every consideration. The souls and spiritual essence of our children are not disabled. Their physical handicaps exist, but their desire to thrive is not diminished."

Physician Dr. Stephen Braddock, Director of Pediatric Genetics at Cardinal Glennon Children's Medical Center in St. Louis, adds: "I always teach new physicians that children with chromosomal conditions haven't read the statistics. These families deserve an informed and thorough discussion of challenges and options they face."

Dr. John Carey, a pediatrician and specialist in medical genetics at University of Utah, believes: "It's important for those of us who have the privilege of caring for children with complex conditions to stop, listen, contemplate, take off our shoes and walk with our fellow traveler."

Although we prayed Simon would become strong enough for surgery to repair his damaged heart, he spent the next 88½ days on a roller coaster of good and bad days. In retrospect, every one of those days was a blessed learning and loving opportunity for everyone who knew Simon. That includes his nurses who recognized his special qualities of peace and perseverance, many of his doctors, and our friends and family members who were privileged to meet this remarkable ambassador of love.

At 10:45 a.m. on December 3, 2010, the tears poured from our eyes as Simon left this world for his eternal home. In my struggle to deal with my grief and understand Simon's purpose during his short life, I decided to write a book to honor him. Simon's story is being revealed to people all over the world. The name of Simon's book is *I'm Not a Syndrome — My Name is Simon*. If you look closely at the cover, Simon says "I Love You" in sign language.

A friend and fellow trisomy mom, writer, and researcher, Pamela Healey, Ph.D., describes the book this way: "Sheryl Crosier's memoir, *I Am Not A Syndrome — My Name is Simon*, of her journey during her pregnancy and her infant son Simon's short but important life, is a story of the heart and spirit. It is also a story of the head that explores the capabilities and constraints of modern medicine and policy, parental rights, and ethical decision making."

God did not bless us with a syndrome. God blessed us with a son. His name was Simon. Simon's story is filled with compassion and outrage. It is a story of a child knit together by the hand of God. Each of his days was written and ordained.

I Am Not a Syndrome - My Name is Simon is available at All StarPress - Books that Change Lives. It's also available at Amazon and Barnes & Noble. Simon's website, www.simonismynname.com has information on the book and on trisomy conditions. A portion of proceeds from sale of this book will go to SOFT, Support Organization for trisomy 18, 13, and Related Disorders.

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