

# INCOMPATIBLE WITH LIFE

**By Rick Santorum (The Southern Cross: May 2010)**

*Incompatible with life.* The doctor's words kept echoing in my head as I held my sobbing wife, Karen, just four days after the birth of our eighth child, Isabella Maria.

Bella was born with three No. 18 chromosomes, rather than the normal two. The statistics were heartbreaking: About 90 percent of children with the disorder, known as trisomy 18, die before or during birth, and 90 percent of those who survive die within the first year.

Bella was baptized that day, and then we spent every waking hour at her bedside, giving her a lifetime's worth of love and care. However, not only did she not die; she came home in just 10 days. She was sent home on hospice care, strange as that sounded for a newborn. The hospice doctor visited us the next day and described in graphic detail how Bella would die. In sum, she could die at any time without warning, and the best we could hope for was that she would die of the common cold.

Karen and I discontinued hospice so that we and our amazing doctors, James Baugh and Sunil Kapoor, could get to work focusing on Bella's health, not her death.

Like so many moms of special kids, Karen is a warrior, caring for Bella night and day and, at times, fighting with health care providers and our insurance company to get our daughter the care she needs.

Being the parent of a special child gives one exceptional insight into the negative perception of the disabled among many medical professionals, particularly when they see your child as having an intellectual disability. Sadly, we discovered that not only did we have to search for doctors who had experience with trisomy 18. We also had to search for those who saw Bella not as a fatal diagnosis, but as a wanted and loved daughter and sister, as well as a beautiful gift from God.

We knew from experience that Children's Hospital of Philadelphia was such a place. Fourteen years ago, we had another baby who was diagnosed as having no hope, but CHOP's Dr. Scott Adzick gave him a shot at life. In the end, we lost our son Gabriel, but we will always be grateful to Dr. Adzick for affirming the value of his life.

When Bella was 3 months old, she needed some minor but vital surgery. Some doctors told us that a child like Bella wouldn't survive surgery or, even worse, that surgery was "not recommended" because of her genetic condition — in other words, that her life wasn't worth saving. So we again turned to the Children's Hospital and found compassion, concern and hope in Dr. Thane Blinman. He told us he had several trisomy 18 patients who did well — and so did Bella.

Next week, we will mark Bella's second birthday. Over these two years, we have endured two close brushes with death, lots of sleepless nights, more than a month in CHOP's intensive care unit, and the constant anxiety that the next day could be our little girl's last.

And yet we have also been inspired — by her fighting spirit, and by the miracle of seeing our little flower blossom into loving, joyful child who is at the center of our family life.

Most children with trisomy 18 diagnosed in the womb are aborted. Most who survive birth are given hospice care until they die. In these cases, doctors advise patients that these disabled children will die young or be a burden to them and society. But couldn't the same be said of many healthy children?

All children are a gift that comes with no guarantees. While Bella's life may not be long, and though she requires our constant care, she is worth every tear.

Living with Bella has been a course in character and virtue. She makes us better. And it's not just our family; she enriches every life she touches. In the end, isn't that what every parent hopes for his or her child?

Happy birthday, Isabella!

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