

# The Love and Death of Lillian and Karl

by

*Matthew and Lucia Markert*

*Jan 2, 2011*

## **Matthew:**

Birth, love, death. Or was it love, death, birth? I'm not really sure. All I know for certain is that love came first. Not just the act of love and conception, but actual love for the child. It starts in the womb, when the mind races ahead to outings, graduations, a wedding, for a child whose gender might not even be known. That bond is already strong when the baby emerges. But birth and death, those are another matter, for which life provides no guarantees.

There is an expected order to our lives in which people are born, fall in love, perhaps have children, somewhere along the way probably lay their parents to rest, and ultimately pass away themselves. The death of a child just seems so improbable, so unnatural, that we feel it violates some moral order. The parents never truly emerge from the grief, and there is too much to process to fit it all into a linear order. So please forgive us if this story becomes disjointed. We'll tell it as best we can.

I'm Matthew Markert (and I'm Lucia), and we've been asked to speak to you on the subject of death.

Our story starts in early 1995, when Lucia became pregnant with a girl, named Lillian. It continues through New Year's Day 1998, when we cradled our dying son, Karl, in our arms for the last time. During this time the impossible became normal, birth followed death, and every world view came into question.

I actually can't say for certain *when* Lillian died. It may have been in the final hours of the pregnancy. The neonatologist reported that she lived 16 minutes, but I am sure he was being generous.

## **Lucia:**

It was a real blow to find out at the six-month pregnancy check-up that Lillian might not even survive until birth. That's when our grieving began. We were committed to give her every chance possible, but the evidence gave the doctors very little hope. During the few weeks between the initial diagnosis and her birth, we read stories to her and sang her songs, in case we wouldn't have the chance to do so later.

I developed pre-eclampsia, and eventually my blood pressure became too high. It was time for Lillian's birth. I prefer to talk about Lillian's birth, rather than her death, even though they are one and the same. I was so focused on Lillian that I didn't realize how serious my condition was. I entered the hospital looking like the Michelin man. After Lillian's birth, I needed two units of blood by transfusion. An aide stayed in the room and monitored me the entire night. That made it even harder for Matthew. In trying to protect me, he felt he had to be strong not only in public, but also with me.

Even as we were losing Lillian, we were very conscious that she had given us tremendous joy. We were amazed by how deep our love for her was, even though we never had a chance to know her.

That first Christmas, three months after Lillian's birth, all I wanted was to escape from the festivities and the holiday cheer. We went to West Texas, planning to see Big Bend. On the way, in Fredericksburg, we bought a window ornament showing a butterfly and flowers. The butterfly is our symbol for Lillian.

**Matthew:**

You probably haven't heard of Gaucher's disease. Neither had we nor our physicians. It is a rare recessive genetic disorder, known only because there are relatively inbred risk populations that exhibit it. Neither Lucia nor I are members of a risk population, and as for inbreeding, I think you'll agree we reached farther than usual across the human family tree to find each other. So how rare is Gaucher's? In all likelihood you are looking at the only mixed race couple on the planet who could produce a child with it. If those odds don't make you feel singled out by the universe, nothing will.

And then there was Karl. Karl was born one year and eight days after Lillian. Obviously we had barely left time for Lucia's body to recover, let alone for us to process the loss of Lillian. But Karl was a wonderful baby, cheerful, bright, and above all, healthy.

**Lucia:**

Becoming pregnant with Karl brought both joy and concern. I was a basket case until we found out that he didn't have Gaucher's disease. It was wonderful to have Karl. At the same time Matthew and I were stressed by major changes in our lives. We were also still grieving for Lillian.

Karl was ten months old when we went to Vermont to scatter Lillian's ashes. Matthew gave a eulogy for her. As I began untying the ribbon around the box of ashes, Karl spontaneously took one end and helped pull it open. Now I have an image of butterflies flying out of the box. We had waited until we felt ready to scatter Lillian's ashes, and I'm glad we did.

**Matthew:**

Karl was so happy and chubby that we called him our little Buddha. I remember that he loved looking up at lights, and me commenting that he would be a holy man when he grew up. As it turned out, he lived just five seasons. In mid December 1997, he caught a fever, which we treated in the usual ways. But his illness continued to worsen, and on Sunday morning Dec 21, we woke to find him having seizures in his crib. We rushed him to the ER, where he was diagnosed with meningitis and admitted to the Pediatric Intensive Care Unit, or PICU.

Antibiotics succeeded in killing the Strep pneumonia that infected Karl's brain. There followed roller coaster days as Karl's body fought an up and down battle against toxins from the now-dead germs. Over the 11 days that Karl spent in the PICU, three sets of CT scans were taken of his head. In the CT scans, light areas showed healthy, functioning tissue. Dark areas showed dying tissue, as if quite literally, the lights had gone out. In the scans we saw the darkness advance until it engulfed nearly all of Karl's brain.

By the last day of the year, a respirator breathed for Karl, water flowing through his mattress pad kept his temperature stable, and artificial hormones regulated his fluid levels. I remember thinking angrily to myself that all this technology wasn't helping at all. But then I looked out from Karl's glass-walled room into the glass-walled rooms of the other babies in the PICU, and saw those babies, who had miracles performed on their bodies and who would return home healthy. I found it reassuring to realize that most of the children, most of the time, would win their battles, even if mine would not.

On New Year's Day 1998, thirteen years ago yesterday, we gave our consent to remove the tubes, the probes, the lines, and let the body go, its occupant having already departed. The head of the PICU himself performed the task. When done, he picked up the newly freed Karl and placed him on my lap, with Lucia sitting beside. As she touched his face and held his hands, I placed my hand over his heart and felt the beating slow, until after a time, no more beats came.

**Lucia:**

Karl's illness and death were a complete shock. When we lost Lillian, we knew that there wasn't anything we could have done to change the outcome. With Karl, there were a lot of what ifs. I felt a lot more guilt and a lot more anger. I also felt despair for the first time in my life. The things that helped me were remembering the joy from Lillian and Karl, realizing that for Karl his life was full and happy, and knowing that our family and friends cared deeply about us and our children.

Going into parenthood, I hadn't expected to learn from my children. Now I know better. Lillian taught me that children are miracles, and gave me the courage to change my life goals. Karl taught me the importance of living life joyfully. When Karl smiled, he smiled for everyone. I'd like to do the same. Kenneth taught me about tenacity and determination in the face of adversity. Elizabeth taught me how deeply a child can love.

**Matthew:**

One thing I learned from the death of these two children was that there is little consolation in hearing that God needed another angel in heaven. I am sure any god worthy of the name could have found a better way arrange this. The one religious sentiment that did touch me was from Hindu philosophy. A friend said that some children need just a bit more to reach the next level, and when they are ready, they pass on. This seemed to fit Karl. It also made me feel that in the 15 months he was with us, perhaps we had helped him on his soul's journey.

We could go on for hours about what we experienced, what we learned, and how we changed. I would like take the time to acknowledge all the other parents who have lost children at whatever stage of life. In a truly benevolent universe, no parent would ever have to bury a child. The most important lesson I have taken from the building and rebuilding of a family is that while death conquers, through love and perseverance, life endures. Lucia and I want to thank Kenneth and Elizabeth for rekindling our faith in that simple fact.

And we want to thank all of you for listening to our story.  
Blessed be.