ESRD: A Sister's Story
By Nicole Allensworth

On March 21, 1991, my life changed dramatically forever. It all started when my brother Frankie, who was two years old at the time, went to a hospital emergency room. A week or so before that night, he had what seemed to be a cold. My mom had taken him to our family doctor's office where he had gotten a prescription for an antibiotic. As time passed the cold symptoms subsided, but Frankie became so weak that he wouldn't stand up. When we went to the emergency room, the doctor ran a blood test. He said either my brother was severely dehydrated or something was wrong with his kidneys. My mom seemed to be okay until she called her boss to get a substitute since she wouldn't be able to teach the next day. As she began to explain the circumstances, she started to cry uncontrollably. I can vividly recall staring at the black and white tiles on the floor as I listened to conversations about the course of events that would drastically alter our lives.

My brother was transferred to Riley Children's Hospital. It housed the only pediatric renal unit in the state of Indiana. He ended up staying there for what seemed like an eternity (actually, it was about a month). My mom stayed with Frankie for virtually the entire time he was in the hospital. She slept in a chair next to his bed. Since I was nine years old and there wasn't enough room anyway, I couldn't stay with them all the time. I stayed with a variety of extended family members and family friends. I accepted that was the way things had to be for the time being. I do remember that I missed my mom, my brother and my bed. Eventually, my mom, my brother and I were able to return home. He was released just in time for his third birthday on May second. He came home with a tube extending for his tummy and a huge amount of medical equipment. He started getting four peritoneal dialysis exchanges at home daily.

For two years, my single parent mom took care of all of Frankie's medical and everyday toddler needs by herself. Then I asked if I could learn to help her by doing dialysis. She was reluctant at first, but I told her that I truly believed that Frankie's condition was a family issue, and I wanted to do my part. She finally agreed, and so I learned how to do the exchanges. I had seen her do exchanges what seemed like a thousand times, so I already had a pretty good idea of what to expect. It was difficult getting used to being on a tight schedule. On school nights we had to be sure to be ever aware of the time because if we did not do the exchanges in a timely manner, we would have to stay up really late at night to do the fourth exchange. Eventually, I got used to the routine, but I can't say it ever became easy.

Frankie has had two kidney transplants. The first one was in July of 1991 and lasted only a few days. Despite the short amount of time that he kept it, it wasn't nearly as scary an experience as the second transplant in May of 1992. The doctors said that as soon as they put that kidney in Frankie, it changed colors for the worse. For several hours, the doctors and nurses worked hard to try to save Frankie's new kidney. In the later part of the evening, I remember my grandmother came out of the ICU to the hall where I was standing. She leaned her back against a wall. Then she started crying and sliding down to
the floor. Then my mother came out of the swinging doors; and she started hitting the wall as she cried. Finally, the medical personnel let me go into Frankie's room. I remember talking to him and trying to laugh for him at a dumb show on the television in his room. I was trying to be brave and to keep down a huge lump in my throat. They had to remove that second kidney that night. They said that his body was just about to go into shock as it tried to reject the transplant. That was when I really realized it was going to take a lot more than a simple bandage and a kiss.

Over the years, our family has learned to adjust better to our situation. Frankie's on a peritoneal dialysis cycler at night. Despite the occasional beeps of the machine at night, to which my mom responds, dialysis is easier now. My mom still tends to be sensitive about the matter of Frankie's condition, but she has improved, and she has kept us functioning as a happy and well-adjusted family. I, on the other hand, rarely get sentimental over our situation. I decided long ago that there is no point in getting upset about something that can't be changed and could be worse.

Well, that's my story. I love my little brother. I'd give him one of my kidneys if I could (So far, I'm too young, so I haven't been tested). Now, don't misunderstand me. We have a very typical sibling relationship. We argue regularly. He does that typical little brother, "I'm going to tell Mommie" thing. He frequently pounces and continues to jump upon my last nerve; but, deep down, way deep down, we adore each other. I've learned that most lives have their ups and downs. In my family, it is my job to treat kidney failure not as a tragedy, but just a part of our lives.

Update: Frankie is now 13 years old and is doing well. He has learned to do CCPD on his own and feels a whole new level of independence. Nicole is currently a student at Ball State University and she too is enjoying a new level of independence from home.