Isabel Stenzel Byrnes

CYSTIC FIBROSIS

"I was very fortunate to travel through life with a twin, and we are tremendously grateful to be alive and have never-ending gratitude to our organ donors."

My identical twin sister, Ana, and I were both diagnosed with cystic fibrosis (CF) shortly after birth in 1972. Ana had meconium ileus, a condition that is often one of the first signs of the disease. The doctors told my parents that we'd be lucky to reach our 10th birthday. This dismal diagnosis thrust my mother and father into a whole new and intimidating world.

As children, we didn't have access to a care center accredited by the Cystic Fibrosis Foundation (CFF). My treatments involved ultrasonic nebulizer aerosols and chest physical therapy three times a day. We also used powdered enzymes to help digest our food.

When our lungs had cultured staph aureus, we were hospitalized for staph and aspergillus lung infections. Then at age 11, we cultured pseudomonas aeruginosa, which started a relentless spiral of chronic lung infections.

Throughout our junior high school years, we were admitted for triple IV antibiotics for two to three weeks at a time, sometimes as often as every other month. To become more independent from our parents, my sister and I started to do each other's chest physical therapy. The powder enzymes and our chronic infections demanded tremendous energy that prevented us from going through puberty, which was a real challenge as a teenager.

We enrolled at Stanford University and attended our first CFF care center. The team changed almost every medication we were using and taught us about clinical trials, cross infection dangers, and educational and support opportunities. I learned about home IV therapy so that I could minimize absences from college courses. With new treatments, I was able to gain weight, have more energy, and thrive in college.

The most dramatic change in my health was a result of participating in the DNase clinical trials at Kaiser, which I joined during my sophomore year at Stanford. After a year-and-a-half, I gained 35 pounds, hit puberty and my lung function increased 13 percent. I was able to live a healthy life that I could not have even imagined before.

About 10 percent of all CF patients have been in a clinical trial, the highest proportion of all disease populations. Desperation was my primary reason. I needed hope that I could plateau or get better. It took a great deal of effort to be part of clinical trials, and I only wanted to be in Phase III trials because I was afraid—and I knew that Phase II trials tested the side effects of medication.

Our dreams for a cure or miracle treatment could not be fulfilled in time, and my sister and I received lung transplants. It was a grueling emotional process to accept that we had done everything we could to fight CF, and that there was nothing else the medical team could do.

I was very fortunate to travel through life with a twin, and we are tremendously grateful to be alive and have never-ending gratitude to our organ donors. We are also extremely grateful to the researchers and physicians who have kept us alive long enough for advances in transplantation technology.

Isabel Stenzel Byrnes was a patient speaker at the ATS 2007 International Conference in San Francisco, Calif.

CYSTIC FIBROSIS

- Cystic Fibrosis (CF) is an inherited chronic disease that leads to life-threatening lung infections and digestive problems.
- The rare disease affects about 30,000 children and adults in the United States, and there is no cure.
- More than 10 million Americans are unknowing, symptomless carriers of the defective CF gene.
- The most accurate way to tell if a child has CF is the sweat test, a diagnostic test that measures how much salt is in a baby's sweat.

Source: Cystic Fibrosis Foundation—www.cff.org