

# ***Whisked Away By A Tornado***

**By Lori Hartwell**

**Author of  
Chronically Happy—Joyful Living in Spite  
of Chronic Illness**

**[www.ChronicallyHappy.com](http://www.ChronicallyHappy.com)**



If I could take a giant step into fantasy, I would transport myself into the film *The Wizard of Oz*. I understand Dorothy, who was whirled away from the safety of her home, and then embarked on a long search to find her way back. That young vulnerable girl always reminds me of my own whirlwind life and battle with kidney disease. Like Dorothy, I too set out on a search for “home,” a place of comfort and hope.

I am 36 years old. For the past 3 decades, I have lived with dialysis, multiple surgeries (35), two unsuccessful transplants, one finally successful transplant and, along the way, being poked and prodded with every instrument known to man.

I was two years old when I was diagnosed with kidney failure, and was immediately placed on dialysis. After just two weeks, my kidneys miraculously started functioning again. Although I had high blood pressure, was on a restricted diet, and endured continuous monitoring, my kidneys continued to function until I was 12. I then had a graft placed in my upper arm and began hemodialysis.

At the time, the medical community was offering much hope with the advent of kidney transplantation procedures. This option looked very promising for me. However, since no one in my family matched my blood type, I was placed on a waiting list.

### **The Wicked Witch**

A year later, I received the call that I hoped would change my life. Unfortunately, “the wicked witch of the west” was strewing obstacles in my path. While I received a kidney transplant, my body immediately rejected it. Fortunately, a new type of dialysis emerged: Chronic Ambulatory Peritoneal Dialysis (CAPD). CAPD differed from hemodialysis, which always made me feel unwell, and allowed greater mobility and independence.

Then, at age 17, I received a second kidney, but it was infected and lasted just three weeks. Exhausted, disappointed, and feeling lost, I received the final blow. The doctors informed me that my chances were slim to none that I would ever have a successful transplant. I have negative type O blood and a very high antibody count.

I had lived with chronic kidney disease for nearly my whole life, and the situation was disheartening. I felt isolated, alone, and angry as hell. Ironically, it was my anger that propelled me forward and into making an important decision. I could sink further into despair, or I could beat the odds and lead the fullest life I could with the time left to me.

Facing the prospect of these options, I chose to live.

### **The Yellow Brick Road**

My path did not clearly emerge for some time, and I had to learn many “tricks” to make my life easier. Certainly, the quality of my life depended upon my ability to take care of myself. My family would do anything to help me on my journey. Still, I didn’t have a map, and I didn’t know where I was headed.

## **The Good Witch Appears**

I was tired and needed to lift my spirits when the prospect of a camping trip with friends was presented to me. I was on my way out the door when I was suddenly struck with the thought, “*Lori, you’d better leave information where you can be contacted. What if you get called for a transplant?*” Another part of me thought, “*That’s nonsense. I haven’t been called in seven years!*” Still, I jotted down the information and posted it on the refrigerator.

Arriving at camp, I was revitalized by the beauty of the mountains and the fresh clean air. The following morning, I went to breakfast, and played some ping-pong and volleyball. Then, from a distance, I could hear someone frantically yelling, “Has anybody seen Lori?”

I ran toward the sound of the voice thinking there had been a tragedy at home. I rushed to the phone. It was Jenny, my transplant coordinator. She said, “Lori, I think we have a kidney for you. You need to get here right away!”

I agreed without much enthusiasm, for I knew that they always called several people, and just two would receive transplants. I also was nagged with the reality that transplantation had failed me twice. Still, despite myself, I nurtured a glimmer of hope. I was nearing my 24<sup>th</sup> birthday, and had spent half of my years on dialysis. Maybe, just maybe, this was my time and it would work. To my amazement, tests showed that the available kidney was a *perfect* match for me. That was nine years ago.

My new kidney works very well. I was very lucky to be given a second chance, and will always be grateful to my organ donor, a young man who lost his life in an automobile accident in Colorado. I also am aware that a transplant is not a cure, but rather, another form of treatment. I could be back on dialysis any day.

## **The Munchkins Listen**

The day I knew that my transplant was successful, I felt unusually blessed. I also was aware that there was a message that needed delivering. I wanted to stand on a rooftop and shout to everyone, “Don’t ever give up. There’s always hope.”

Those of us who live with kidney failure experience the same emotions of anger, guilt, fear of the unknown, depression, and a “why me?” syndrome. We must learn to express ourselves in a positive way and reach out to others.

## **The Scarecrow**

Like the scarecrow in *The Wizard of Oz*, I had to find my brain in order to cultivate a high quality of life. I had always asked questions about my illness, but now I became even more involved in my quest for knowledge. I questioned my doctors’ decisions and demanded answers. I learned about diet, exercise, and what my lab values meant. I joined Toastmasters (a public speaking group), wrote many speeches, and expressed myself through short stories, cartoons and poems. I found my true passions in life: arts and crafts, music, animals, table tennis and dancing.

I also wanted other people with kidney disease to know that they are not alone. So, I founded the Renal Support Network, a non-profit organization. This network recently published the seventh edition of its directory for kidney patients and families. Eight thousand copies currently are distributed throughout Southern California. In addition, we host an annual Prom for teenagers who live with kidney disease.

### **Tapping My Ruby Shoes**

I wanted to work in the renal community, but I had not progressed far with my education. What I did have, however, was loads of personal experience, and I reasoned that had to count for something. Prior to accepting the position of editor for *For Patients Only* and *Contemporary Dialysis & Nephrology*, I was a product specialist for In-Line Diagnostics. Following that, I assumed the position of western regional sales manager for Medcomp, where I managed seven states and 14 representatives. I also increased sales in my territory by 40 percent.

My responsibilities have allowed me to visit more than 500 dialysis units and hospitals in 30 different states. Importantly, I have been in a position to bring mutual understanding between patients and healthcare providers.

Today, I run my own company, Hartwell Communications, was appointed to California Governor Gray Davis' Rehab Council and wrote a book titled "*Chronically Happy—Joyful Living In Spite of Chronic Illness.*"

### **The Tin Man**

Still, something was missing. I had to find my heart, something I had avoided for fear of rejection. In early 1996, after I'd joined Toastmasters, I met Dean, the man I married. I had previously gone through "dating hell." Dean was different. He wanted to know everything about me, and *didn't* change the subject when I spoke about my hopes and fears. We had many things in common and enjoyed each other's company. Our friendship evolved into love.

We have now been married for five years. Our family includes Johnny, an African gray parrot; Kanyon, a border collie mix dog; Jafar, a doberman/shephard mix dog; and Sophie, a gray tabby cat.

### **The Lion**

Along the way, like others, I had to find my courage. Kidney disease presents many obstacles, including side effects from medications, peritonitis, infections, and the possibility that a transplant may not work. I believe it's all worth it. For along with those obstacles, comes a unique chance to triumph.

### **Home at Last**

I wake up in Kansas everyday knowing there is a chance my health status might change and, once again, I'll whirl into the unknown. Yet, I know that as I travel down the yellow brick road I'll never lose my brain, my heart, and my courage. No matter what, like Dorothy, I'll keep those qualities intact.