cfri Cystic Fibrosis Research Inc.

Research for Living ~ Partners for Life

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Dear Friends,

For the last five years, I've fought end-stage cystic fibrosis (CF) lung disease. Breathing. It's something so simple. Something most people take for granted. For those of us with CF, breathing can mean the ability to live past the age of 20 or even 30, to obtain a successful career, to raise children, and to travel.

For me and all my cystas and fibros, breathing is a luxury and a full-time job. Every day I fight to breathe.

I think of myself as a cystic fibrosis survivor. And in my heart I know it's true. Today I'm 27 years old and live in San Francisco. I was diagnosed with CF in 1990, when the average life expectancy of someone living with CF was only 18. While a person born today with CF is projected to live into their forties, unfortunately, last year the CF-related median age of death was only 30 years old.

When my mother was seven months pregnant, she went for a routine ultrasound and the doctor discovered a blockage in my small intestine. Called meconium ileus, this condition is seen in 1 in 5 infants with cystic fibrosis. After a few weeks of increased monitoring, the doctor observed no change and advised my parents to plan on having a surgeon ready for my arrival - and to mentally arrange for the possibility of a sick infant. At one-day old, I won my first battle of survival. The surgery to remove the blockage was successful, but the fight was just beginning.

When I was a few months old, my parents noticed I had a lethargic demeanor. My mom went to the local library and, after lots of research, came across a phone number for a cystic fibrosis specialty center. My parents immediately called and were advised to rush me to the hospital, where I was diagnosed. I was then put on the right medical regimen for my disease with the hope for survival. My parents learned how to give me the correct number of enzymes before meals so that I could digest my food and gain weight, and to give me chest percussion treatments along with nebulized medication to clear my lungs of damaging mucus. They learned how to help me breathe!

As an adult with CF, breathing isn't easy. It takes a vigorous medical regimen and hours of inhaled nebulizer treatments, and most often, taking steroids. It also often includes sinus care, general intestinal care, possible diabetes care, mountains of pills, feeding tubes if we're unable to sustain nutrition, IV antibiotics, and sometimes procedures and surgeries. Living revolves around breathing, gaining weight, staying active, and - most essentially - keeping a great quality of life while surrounded by loved ones.

To many of us, the hospital is our second home, and for some, it's our first. Transitioning to end-stage lung disease was extremely difficult. Unfortunately, the "work hard, play hard" attitude I

developed as a young adult came to a halt when my lung function dropped to an all-time low of 16%, causing me to lose close to 30 pounds. I had to put my dreams of living a "normal" social, active, and independent life on hold and make health my first priority. Lung transplantation, at that point, was my only option of survival.

Like all my cystas and fibros in this world, I am a born fighter. Today I'm the product of hard work and sheer determination with new lungs, two years post double-lung transplant. I'll never forget the moments I struggled to gain enough oxygen to walk or sleep, but more so I'll never forget those first breaths I took with my new lungs.

I had never felt my lower lobes expand until the day I received new lungs. To say that I'm thankful to my donor could never be enough, and unfortunately, the words I have make it so that the depths of my gratitude will always remain unfulfilled. But the fight against cystic fibrosis is never over.

In fact, many lung transplant recipients do not survive more than five years due to rejection. As I write this letter, I am in chronic rejection and desperately in need of another double lung transplant. In the first 18 months after transplant, I regained independence, traveled, exercised, and met the love of my life, who I joyfully married on October 28. Even though I now need more help than ever, I'm overall mentally and emotionally stronger than before the transplant in spite of rejection.

So here I am, still the product of fearlessness, drive and strength, fighting what I hope will be my last battle…to be re-transplanted.

In spite of the state of my health, I'm honored to be alive to encourage and connect with my peers as a source of information, support, advice, and experience.

Living with CF is a life-long battle. Together let's help find a cure for cystic fibrosis, so those born today with CF never have to fight to breathe. And so that the initials "CF" no longer stand for this disease, but for the words, CURE FOUND!!

I urge you to give what you can to CFRI. CFRI helps us win battles with the dream of eventually winning the war. Let's do this together!

With hope,

Caleigh Haber

PS. CFRI is our partner in living. For those of us with CF, CFRI provides programs and support to improve our quality of life, and they fund ground-breaking research to move us closer to a cure. Please give today and help them help us!