

Loyola Donor Service
Wednesday, April 18, 2001

I'm sorry I missed the donor service last year. The week before, I was called away at the last minute to attend to some business. I did, however, write a letter to the party responsible for my missing the service, to give them a piece of my mind. In my first paragraph, I tried to explain how much this service means to me, and how much they inconvenienced me... It read --

“Dear Donor Family,

My name is Steve. I live in Illinois and have lived in the same general area all of my life. I've been married to my wife Laura for over 11 years. I truly believe I love her more than when we fell in love 14 years ago. We have no children, but we share 10 beautiful nieces & nephews all under 10 years old. Because of you, I celebrated my 40th birthday 4 days after my surgery. Because of you, I'll be able to share my nieces' and nephews' lives, go to little league games & gymnastic meets, and I won't worry about leaving my wife alone.”

We don't have time for the next 3 pages of that letter...

I was listed for a double lung transplant on September 8, 1997. At that time I was told that I would likely wait a year, give or take a few months. I waited over 2 ½ years. That's 31 months. That's 134 weeks. That's 943 days. But I wasn't counting.

For 3 years, every day I had 8 hours of pounding on my chest, 4 or 5 hours of meds, some routines that were just exhausting... and some simple medical instructions that my sister Sue gave me: Inhale, Exhale, Repeat.

I think about my donor family every day. While I was waiting for my transplant, every night, after the last of my four 2-hour therapy poundings -- while I was winding down I would sit in the dark in my bed for about 30 to 40 minutes before I went to sleep. I would say my prayers. I'd ask a lot of people for some help... Sometimes I'd drift off for an hour or so, wake up and continue where I left off. I'd always think about my future donor, and I'd pray that they were enjoying their life... And think that maybe I could hold out just a little bit longer and give them a little more time to finish what they had to finish. When the wait started getting longer and longer, and I started getting lesser and lesser, there were more than a few times that I looked up at Him through the corner of my eye and said, “Lord, I hope you know what you're doing!” – Apparently he did.

I had 4 false alarms before that call on April 8th ... Every time I got a call, I realized that someone had just passed away, and I knew that some family was suffering... And I knew that they were also reaching out to try to save my life.

I know that my donor was young. I can't even imagine the devastation that they were facing when my donor family chose to save some lives. And they saved my life. They've shown me something that I've always known... That there is pure goodness in this world.

I was truly able to appreciate the feeling of losing someone close to me before I got my first call. My Dad was diagnosed with cancer several months after I was listed. He passed away almost a year before I was transplanted, one week before I got my first call. He's been one of my heroes for 40 years. He was a truly beautiful man. He wanted so much to see me here, doing this – I know he's watching me now... I can feel his smile. I had the honor of giving part of his eulogy... I had to crank up my oxygen to be able to tell everyone what my Pop meant to me... I offered them the opportunity to turn off my oxygen if I babbled on too long. Fortunately for me, and unfortunately for Penny & Michelle, you don't have that option available to you any longer!

I've got so many heroes in my life now... So many people who've impacted my life in some way and helped me through this. I've been with a wonderful doctor for 28 years. He's helped me through so many things in my life, and he told Laura they'd *both* get me through this. The best thing he ever told me was to take this one day at a time... He told me to survive today and let him think about tomorrow. Now I'm with a whole lot of wonderful new doctors... Aside from my medical heroes, there are so many people who helped me get here. Laura has always been here for me... She, my sister Karen, and a wonderful therapist pounded on me for 8 hours a day, 7 days a week for 3 years! My family and friends were unbelievable support! And there is a group of pre and post transplant people here that made my desire to keep going very strong... You never know when a smile, a pat on the back, or someone just recognizing that you are still alive and that they care... Makes that day just a little bit easier to face.

There's so many people I'll never know about. I'll never know if there was some friend, volunteer or compassionate healthcare worker that planted a seed in my donor family's mind that eventually caused them to consider donation...

Now days... I open my eyes in the morning, stretch and take a breath... And I don't hear any gurgling! It's been a year, and I still walk around in complete awe of how this feels! The doc gave me permission to swing a golf club 6 weeks after my surgery. I fit a few rounds into my schedule last summer... I still stink... and it's absolutely wonderful! After 3 years off, I was back at work 10 weeks after my surgery. There is a double flight of stairs from the trading floor to my offices that I hadn't climbed in 10 years. I didn't even go DOWN them in the last 5 years. Now, every chance I get I bound up them 2 steps at a time... And every time I get to the top I smile.

For the past 40 years I've had to work every day to stay alive... for 30 years, 2 or more hours clearing my lungs reminded me daily of what was wrong with me, what I had to do, and what the consequences were if I didn't... Now, I still have to do a lot... I constantly monitor my health. I take 40 pills and inject insulin daily. I deal with illness. I'm afraid of what the future will bring... But instead of being reminded of my condition by discomfort or difficulty, I'm reminded when I walk or run or laugh or talk or sing!

One of the final paragraphs in the letter to my donor family read --

"It's difficult for me to share the joy I feel and at the same time reconcile that with the loss I know you've suffered. I do know what you did was a purely selfless act. And an act of pure goodness. After 40 years of living with cystic fibrosis, I hope you can understand what you've done for me. You did not just save my life. You've given me a life I've never known; I've never, EVER been able to breathe this well. I don't know if I can do anything to ease the pain you feel, but I will always do my best to honor the gift you've given me, and the loved one you've lost. My wife, my family and I will never forget what you've done for me."

I'm not sure if I will ever meet the family who saved my life, and I'm unsure how I can honor the memory of their loved one. The only way I can think of right now is to savor every minute that they've given me... And try to help other people who are now walking in the shoes I've left behind.

When I leave this place for good, I would like the world to have been a better place for my having been here. I personally know that there is a child, and a family who've made my world a better place... Actually, there are 5 donor families who each made my world a better place, and a better place for so many people!

On my last hospital stay, just before I was listed – Three years before I was transplanted, in a wheelchair we passed the chapel on the way to a test in the bowels of Rush Medical Center. When the test was finished, I asked if we could stop at the chapel for a few minutes. The transportation person apologized and said that she wasn't allowed to stop along the way. On the way back to my room, she rolled me into the chapel. She grinned and said, "wait here, I'll be back in a few minutes..." I had a little chat with God... And I asked for some help. In my little nightly discussions, I asked everyone I could up there that when the time comes... comfort my donor family, and help them to make the decision that they made. In my wildest dreams I never imagined that I'd get this much help!

Thanks.