

FEATURE STORY

OUR TRANSPLANT JOURNEY

by Cheri Volner



My name is Cheri Volner and this is my family's story. I title this story "Our Transplant Journey" because that is what it is, a journey. You must journey to the avenues of knowledge that teach you about the process, how it is done and if you are even eligible. It is a journey of learning, emotions, healing and of renewed life.

Our transplant journey began in 1995 when my husband was diagnosed with COPD/Emphysema. It was at this time that his breathing was becoming to the point that trying to work every day was becoming more and more difficult. He then became disabled and had to stay at home. The medications, inhalers, nebulizers and oxygen therapy (normal treatments) became part of our everyday lives.

Even with all of the medications his breathing became progressively worse. This is what COPD does, it just slowly envelopes the lungs until they just can't function. There were offers of experimental drugs, which we tried, but were ineffective for my husband. We then explored the possibility of removing the diseased part of the lung only. But that hope quickly faded as we found out that there was too much diseased area. Finally, we were told by the pulmonologist that there just wasn't anything else that could be done.

My husband had been talking to a friend who suggested he look into getting a transplant. He asked the pulmonologist we were seeing about getting a transplant. He told us he was sorry but my husband was past the age that this could be done. He stated my husband might have about three years left. We left that office completely broken.

After the initial shock from that announcement wore off, it was then that we began researching the whole transplant idea. My husband contacted Barnes-Jewish hospital in St. Louis, Mo. The nurse coordinator of the program contacted us and explained a lot about the processes and procedures that would lead up to the decision to see if he would be eligible. Our questions were:

1. Age...since we had already been told that age was a problem she confirmed for us that, NO he wasn't too old. My husband was 68 when he had his transplant and 67 at the time of our initial inquiry.
2. Mortality...I was also very nervous about the possibility of my husband dying while in surgery. The nurse assured me if he passed all of the tests and qualified, that he would not only come out of surgery, he would also have a very good quality of life.
3. Other issues of concern were of course financial. All options were explained as to how to get the coverage needed for the procedures and for all the medications.

After having all of our questions answered we moved forward with doctor visits, completing a lot of paperwork and a huge battery of tests. It all proved to be positive! My husband was positioned on the transplant waiting list according to the severity of his condition. He was high on the list because his disease had progressed exponentially.

During our journey we encountered several road blocks. I was one of them. I was diagnosed with breast cancer. I needed biopsies and of course surgery. During this time my husband was on the list for a "perfect set of lungs", because he had never encountered a common virus as a child. If you haven't had this virus and get a set of lungs that has, the possibility is great that you will get the virus, which can be life threatening right after a transplant. A drug is available that you can take to help prevent getting the virus, but it is very expensive and isn't covered under common insurance plans.

By the time all of this was completed, my husband's condition was at the point he knew that if he didn't receive a transplant in the very near future he wouldn't live. So he asked to be placed on the "any lung" list. It was one week to the day after going on the "any lung" list that we received "the call" on May 16, 2012.

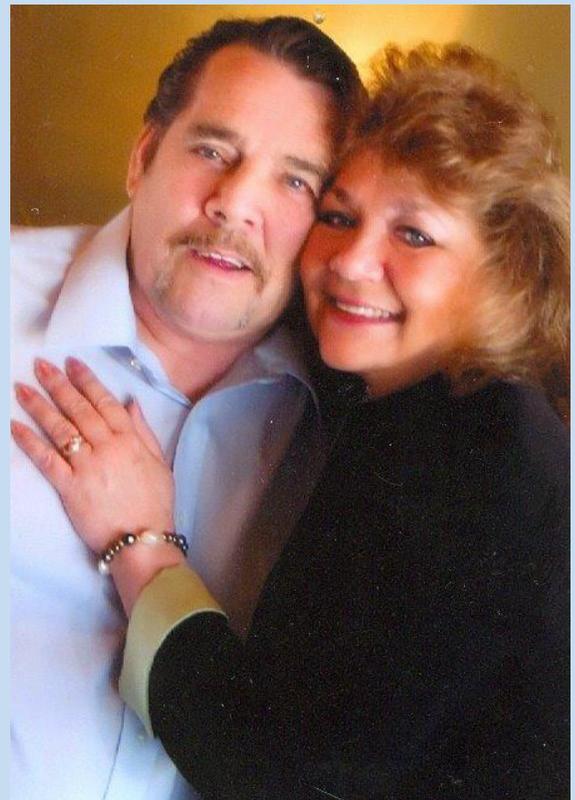
What an exciting, scary and sad time all at once; so many emotions. I compare it to the news of it's time to have the baby! Yet, as excited as we were to think that the transplant was really going to happen, the fear of such a huge surgery loomed in our minds along with the reality that someone else died and their family is suffering. We felt somewhat guilty.

The days and weeks that followed were ones of significant work. My husband had pulmonary therapy for two hours every day, Monday through Friday. All of the medication was certainly an adjustment for his body. Not to mention the healing process and just getting used to the power of breathing again.

I would say to others who may need to make a similar journey, make sure you get all the information you can from a transplant hospital. Not all doctors are well versed on the subject of transplant. Taking the time to research and learn about transplantation is what made the difference in our life's journey.

For us, and many others that I met along the way, this was, and continues to be, a very positive experience! Our journey continues, as we again begin to work on our life dreams and be active in the lives of our children and grandchildren. Most of all...we just enjoy...life!

"You must journey to the avenues of knowledge that teach you about the process, how it is done and if you are even eligible. It is a journey of learning, emotions, healing and of renewed life."



Lou and Cheri Volner

A special thank you to the doctors and nurses at Barnes-Jewish Hospital St. Louis for all of your excellent care!