Patient Perspective: Going Through a Clinical Trial

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When I was diagnosed with idiopathic pulmonary arterial hypertension in late 2011, I was devastated, but I knew I had to be strong for my family. At the time, I had been juggling my life with being a wife and mother to two young children and working full time. I had difficulty with my breathing for years, and even after describing my symptoms of shortness of breath, chest pain, passing out, and feeling dizzy, the numerous doctors I saw told me that I was most likely depressed, had anxiety, or was just stressed due to being a mother.

A friend of mine recommended a cardiologist in Monterey, CA. He discovered that my heart was enlarged and made arrangements for me to see the pulmonary hypertension (PH) team at Stanford Hospital. I met with Dr Roham Zamanian and the rest of the team and was hospitalized that same day. That was the day my life completely changed. I was no longer a person who thought about living into old age; now I had to think about living as if every day might be my last.

The PH team started me on triple therapies, and I was to titrate rapidly due to the damage done to my heart. Each month that passed I was expecting to feel a difference in my condition. I was no longer passing out, but I still had chest pain and difficulty breathing due to how advanced my PH was. In March of 2012, my PH team started preparing me for a double lung transplant. I did all the necessary tests, but was hesitant because my daughter was just starting kindergarten and I didn't feel ready.

In June I was approached again and told that I needed the transplant if I was to prolong my life, since my body was not reacting to the medications as well as they had hoped. In August of 2012, I was officially added to the lung transplant list. I was scared and didn't feel ready. Dr Zamanian called me that same day and reassured me that I needed to be on the list; then he asked me if I was open to trying a trial medication.

I immediately agreed and started my journey with a clinical trial. Dr Zamanian and Dr Edda Spiekerkoetter were the doctors that I would work with during the trial process. I started taking the trial drug and did regular blood tests to ensure that I was within the range that was required. Within a month I couldn't believe how "normal" I felt. I wasn't winded when climbing stairs, my chest pain was gone, and I felt so much better. Within 2 months' time, I needed to follow up with the lung transplant team; when I described how I was feeling, my transplant doctor put my status on the lung transplant list on hold. I knew I couldn't forget that I had PH, but I felt that I could live a life that was productive for as long as I could.

The trial therapy added to the standard of care gave me 5 years before I needed a heart and double lung transplant. During those 5 years I was able to volunteer at my children's school, enjoy birthday parties with them, and travel in and out of the country, making memories along the way.

Due to the nature of PH, when you start to decline, it can happen fast. In December of 2016, my transplant team encouraged me to start the lung transplant process again. In my mind I was strong and thought I could make it a couple more years without transplantation, but my body was giving out. In January 2017 I was admitted to the hospital at Stanford with a central line infection. In the next few days I started to rapidly decline and was placed on the transplant list on February 14 for a heart and double lung transplant.

My condition improved and I was allowed to go home and wait for the transplant call. I was home for almost 2 months when I started to cough up blood and was taken again to Stanford Hospital. I don't remember what happened during that period; I woke up 5 days later and realized I was connected to the extracorporeal membrane oxygenation machine in the intensive care unit.

As I waited for my transplant, I would think about the extra time I gained with my family due to the trial therapy in addition to excellent care. Those memories brought me a lot of happiness, comfort, and peace. I was transplanted on June 4, 2017, and though I no longer have PH, I hope that my experience with trying the trial drug helps some other PH patients and encourages other to try trial drugs in the future.

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DOI:10.21693/1933-088X-19.2.61