Lung transplant, my story...

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Before I begin, I would first like to thank the many people, without whom this may have never happened. To the doctors and nurses and everyone else at Johns Hopkins who have been absolutely amazing. To countless friends and relatives, I can't begin to name them all or to thank them all personally for all of their support and prayer. I feel that everyone has gone through this together with me. To my immediate family, my sons and daughter-in-law who sacrificed tremendously beginning with my son John's accident in February, 2014 and continue to do so. To my dear wife Diane who has been steadfast through the ordeal of my surgery, but even more so with our youngest son being wheelchair bound. And very importantly, I want to thank the donor and his family for their tremendous sacrifice. And most importantly, I thank God for guiding me through this. I know he has a plan.

I will begin back in 1990 when I was living in Virginia. It started one day when I was not feeling well. So, I decided it might be good if I headed over to Kaiser Permanente to see if I could find out anything. The first doctor I saw there believed that I had pneumonia, or something similar. Another doctor looked at the X-rays and said it did not look like pneumonia to him, but rather, something called sarcoidosis. Now, this was something I had never heard of. However, I don't remember pursuing this in any way. Time passed.

I had always been proud of and taking for granted my apparent good health, so I never saw need to go to the doctor. Life went on and years passed. Literally, years passed. The ten or so years following 1990 were kind of a blur regarding my health. I don't recall much in regards to any decline in my health during those years. There were periods where I had a chronic cough that I remember. Diane seems to remember a whole lot more that my lung function was declining during those years.

As I said, I was not one to ever go to the doctor. However, one day at work I realized I was quite out of breath. I remember it very well. It was July 13, 2001. I made an appointment to see my doctor. It would be five days later. However, it was soon apparent that I could not wait. Went to the Bowie emergency room in the evening. The main thing I remember from that visit was the albuterol nebulizer treatment which lasted about forty minutes. Went home feeling pretty good. Went to bed. Woke up a couple hours later with a headache, irregular heart beat and other symptoms that I can't remember. I do remember they gave me a list of ten possible side effects of albuterol. I had almost all of them. Went to another emergency room, the other one having closed at 8pm. Don't remember them doing anything to be of any help. Went back home.

By now about twelve hours had passed since first being out of breath. My health clearly deteriorated dramatically during that time. My right lung felt like a brick and for the next 20 days I could not sleep lying down. Diane flew to Korea during that time. I cancelled my plans to go with her. With only twenty days having passed, I did not yet realize my life was changed forever. The pain in my lung slowly subsided. However, it did come and go for about three years. Sometime after those first twenty days it gradually became clear that my lung function was way less than it was just weeks earlier.

I didn't really like my first pulmonary doctor. She wanted to put me on steroids just ten minutes after meeting her for the first time, and without much explanation. She was kind of cold and all business. She performed my first bronchoscopy and biopsy. Her diagnosis was pulmonary fibrosis which was discovered five years later to be incorrect. Soon after that diagnosis, I read somewhere that the average life expectancy after a diagnosis of pulmonary fibrosis was about four years. It would be another seven years before I finally gave in and started taking prednisone. In hind sight, I believe prednisone was good for me. And I believe that if I had started taking it way earlier I may have been better off. I still take it.

True to form, I was not good about going to the doctor. My mother-in-law called me at the end of March, 2003 to yell at me for not seeing any doctor for over a year. So I went in for a regular physical on the first Monday in April. My doctor saw something right away and sent me to a specialist. I saw him two days later, on Wednesday. He took a look for about three seconds. "We need to surgically remove your testicle Bob. We will not test it before removing it, so as not to disturb the integrity of any contained cancer." It was removed two days later. It was then tested and found to be malignant.

I connected with Johns Hopkins in 2006. That is when they performed another bronchoscopy and biopsy. It was correctly diagnosed this time as sarcoidosis. There was some initial talk then about a lung transplant. The idea seemed so alien and distant. I did not believe it would ever happen. By 2007 I had a small army of Johns Hopkins doctors at my command. However, as 2008 and then 2009 came and went, I was back to my habit of not going to the doctor. I was not seeing my specialist, Dr. Moller, very often. I was supposed to see him every six months. It became like one or two years in between visits. I even weened myself of prednisone. Around 2009 I got an oxygen generator and a backup tank. I barely used

the generator and they both got buried in a closet. During these years my lung function progressively got worse. Late in 2013 I finally got an oxygen tank I could carry over my shoulder. I began sleeping with the oxygen generator running. I was soon upgraded to larger tanks on wheels that I would drag with me everywhere. I was now pretty much having the air tube in my nose 24 hours a day.

It was about this time, on February 23, 2014 that my son John had his accident, rendering him a quadriplegic. I took off work because of that, but due to my health I never went back. John and I clearly had a connection.

Early in May, 2014 I decided I would walk everyday without oxygen. My thinking was to use as little oxygen as possible. I would carry the oxygen with me in case I needed it. I managed to walk a third of a mile on the third day, although it took about an hour. I stopped every three or four steps. I managed to walk like this for six days. Soon after this I was told I should use a lot of oxygen all the time. In the evening of the sixth day I was sitting on the sofa. It was about 7pm. My legs had been getting more and more swollen. I realized it was just not safe for me to go to bed that night in my own bed. I thought at first that I should go to the Bowie emergency room. I soon decided that I should go to PG hospital. No... Of course I should go to Johns Hopkins. I went to the emergency room there. They saw right away that they should keep me overnight. They kept me for eleven days. John was right next door at Kennedy Krieger Institute. Due to an underground tunnel, you could walk from John's room to my room without going outside. It was during these eleven days that I met Dr. Pali Shaw for the first time. She said "we would like to begin a work-up for you to have a lung transplant". By now, the idea did not seem like a distant fantasy like it did a few years prior. This was real. I was discharged on day eleven after they were satisfied with removing 18 pounds of fluid from tissue throughout my body.

On our wedding anniversary, on July 1, Diane and I went to a movie. At the end of the movie I realized my oxygen had run out. I walked to the car stopping every two steps. Diane drove the car right up to the door. My O2 saturation measured 75% when I got home. That is basically lethal, but I survived.

There is a side effect of my condition called pulmonary hypertension. I had a specialist just for that, Dr. Damico. I went to see her in July. She took one look at my swollen legs (a side effect of the side effect (pulmonary hypertension) and the same reason I was hospitalized in May). "Bob, we're putting you in the hospital". Stayed for another ten days. The exact same thing happened again in September when I had an appointment with Dr. Shaw.

Around the middle of October 2014, I met the surgeon, another Dr. Shaw. "Very nice to meet you Bob. So what we are going to do is make an incision across here. We open it like the hood of a car, pop the old ones out and in go the new ones. And you are good to go". I'm thinking, "it sounds so easy, count me in". But then he said "I have to warn you. One out of five wished they had not done it. They would rather have died then go through what they went through after surgery" I'm thinking "o---kay". This stuck in my mind for sure.

By then I had passed most of the tests and hurdles to qualify for new lungs. On October 22 they called me to tell me I was on the transplant list. Because of the severity of my condition, I was given a rating that bumped me ahead of most people on the list. So, just ten days later, on November 1, 2014 at 8:30 pm, the phone rang. It was surreal to hear someone say "We got some lungs for you". I was so nervous. And Diane, you gotta love her, says something along the lines of "Are you sure you want them?" She was trying all kinds of alternative medicine on me and was hoping I could show some dramatic improvement. Weeks earlier I said "If that happens, I might consider postponing a transplant". However, It was now a no brainer for me. I was only getting worse. "I'm going for it". The lady on the phone told me to take my time and have someone drive me up to the hospital. They settled me in for the night. I was so excited the next morning when they rolled me into the operating room. The anesthesiologist said "you're gonna feel a little dizzy". I had already come to love this moment when the ceiling starts spinning. One of my kids saw me soon after surgery. He said my eyes were taped shut and I looked like a corpse. The next thing I know, I wake up in my hospital room about 48 hours later. Oddly, the only thing I was worried about was having my arms restrained during surgery, being that my claustrophobia had gotten quite a bit worse due to my condition. I was afraid I would find myself restrained when I woke up. They restrained me while I was knocked out and removed the restraints before I awoke, so it became a non-issue. However, for at least a day I thought my right arm was restrained. It was actually a splint for my I.V. I guess I was still out of it.

Around the day I awoke, my male nurse came in and said "OK, get out of bed". Of course he was kidding. Actually, he was not kidding. I said "Yeah, like I'm really going to do that!" "You're getting up and you are going for a walk". I could not believe how difficult it was. My new lungs were obviously doing very well. However it was a different story for my legs, and the rest of my body for that matter. I was very weak.

Physical therapists started showing up in the morning. Making me get out of bed and walk. They were not easy going like the nurses and techs. They were. task masters who tested my limitations. It was tough but I was improving in my walking.

I was genuinely amazed at the complexity and effort afforded to take care of me. Two nurses in the daytime, one at night. All well trained to take care of transplant recipients. One level down from the nurses were the techs who did a lot of the nitty gritty stuff. This freed up the nurses to do their jobs. The Phlebotomy people showed up twice a day, often in the middle of the night, to draw blood. Then there were the respiratory therapists who came every four hours, day and night, to give me breathing treatments, make me do breathing exercises and do some coughing. The X-ray tech rolled the X-ray machine into my room every morning. Many different doctors visited me daily.

I soon noticed that the walls in my room had designs on them. These were the best kind of design. They moved... Constantly. And another cool thing was that the whole area in front of my window was full of small 2mm bubbles, also constantly in motion. I described this to Diane and some of the nurses and doctors. They were amused. When I moved to my new room on the tenth floor, I got to take the designs and bubbles with me. One day they gave me oxycodone. Big mistake. They gave it to me one hour before my first big meeting with my lung transplant coordinator. I was very far out in left field and also tried my best to stay awake. She and Diane got a big kick out of it. For more than two days I thought the meeting had taken place in some other completely different room. It actually did not. I love my meds.

I began to think about what Dr. Shaw had said about three weeks earlier. So where were the difficulties that would make me want to be dead instead? Well, for me it wasn't pain. I never had any after the surgery. Most people experience a lot. Could it be the catheter? This was my first experience with a permanent type catheter, let alone any catheter. Yeah, I peed in the catheter any time I needed to, but I sort of didn't like it. On the other hand, it was good to just lie there and pee. Getting up for anything was a major operation. First there is the catheter connected to its collection box, twisting and pulling when I move. Then there are three third inch tubes coming out of my chest draining blood. One for each lung and one for the heart cavity. Each with their own larger collection boxes. There was an epidural on my back for pain. Maybe that eliminated the little pain that may have been there. There was a tube coming out of the side of my neck. Don't remember what that was for. I think it was actually removed around the time I finally woke up.Then there was the I.V. In my right arm. I had what is called a PICC line on my left upper arm as well. And luckily, I didn't have to poop for several days. I did, however get up to walk a couple times a day. The nurses or physical therapists would hang my four collection boxes on the I.V. pole and off we would go. Sleeping was kind of tough with all this crap. After six days I started pooping and soon it was three or more times a day. So each time, I had to call a tech or nurse to help me get to the bathroom. They would hang the collection boxes on the pole, unplug the I.V. electrical connection from the wall. I could soon walk all this stuff the ten feet to the bathroom by myself. After a few more days I could hang them all myself, pull the plug myself and make it to the bathroom without calling anyone. Wasn't easy though.

Now, the thing that was really the most difficult was not being able to eat or drink. So when the nurses asked if I needed anything else I always asked for a pepperoni pizza and a large Doctor Pepper. I did not even receive fluid through the I.V. except for minimal saline solution for administering some drugs. I asked about it. They said they needed to keep my lungs dry and that I would survive it quite well for many days. This went on for eight days until they started giving extra fluid through the I.V. Around the ninth or tenth day I started getting nutrition through the I.V. Everyone was hoping I could eat as early as the fifth day. However, I kept failing what is called a swallow test. I was allowed two little ice chips per hour. The idea of the whole thing was that I could chew and swallow the solid ice leaving minimal fluid that could be aspiroated into my lungs. Many nerves were cut during the surgery and I wouldn't know to cough if fluid got in my lungs. Not a good thing. I lived for those ice chips. The savvy nurses and techs kept the ice chips across the room, knowing I couldn't get up and walk by myself. I confess I did cheat and got the less savvy to leave whole cups of ice chips within my reach. I would go through the whole cup in twenty minutes including drinking it drop by drop as it melted. I would do my best to destroy the evidence so that I could ask the next person who came in to give me another cup. Diane was staying with me pretty much 24 hours a day and was making me stick to two chips an hour. However, I was quite bad and did all this while she was out of the room or sleeping. I even managed to steal her ice water when she wasn't looking. I was really bad about this but my life was quite centered on those ice chips. I lived for those ice chips. I thought I would cherish ice chips for the rest of my life. Now, I don't want to see another ice chip. I was very careful to put only a little ice or water in my mouth at a time and do a lot of coughing if I thought some went down the wrong pipe. Luckily no problem ever developed due to my being so bad.

The fluid and nutrition through the I.V. was not really cutting it. I was down to 113 lbs from my preop weight of 120. On the eleventh day they rolled me down to surgery to have a stomach feeding tube put in. They rolled me into the operating room. Dr. Cromwell was kind of a funny guy. "Bob, do you know the song "Eating goober peas" He sang it to me. Ironically, the next day I finally, partially passed the swallow test. So on day twelve I was able to eat and drink. The partial part means I could only drink thickened liquids. But,, there was no limitation on the food. It would be two weeks after discharge before I would

fully pass the swallow test. I continued using the feeding tube at night, even for more than a month after discharge. Didn't really need to use the feeding tube, so I got permission to stop using it. I did not experience pain following the transplant surgery, but the stomach tube was painful and annoying. It twisted and turned. It leaked and it bled most days. I was told I would have to keep it for four months until I healed enough for it to be removed. Finally, on March 20, I went to Dr. Cromwell's office. "Okay Bob, are you ready? This us going to feel like a punch in the stomach". He then just yanked it out. I did not hurt as much as I thought it would. He said the trauma of yanking it out would prompt it to heal. However, short of surgery, that was the only way to remove it.

Now, let's get back to November and me being still in the hospital. One by one, they removed the tubes from my chest. As I said, the one in my neck was there for just a couple days. They also removed the catheter. The nurse just yanked it out. That had to have been the most painful moment of all I experienced in the hospital. They removed the PICC line as well. A blood clot formed at that location so I would be on blood thinners for a few months. I felt so good to have all that crap removed. I would still have the two foot tube hanging out of my belly until March.

It was fantastic to be able to be discharged the day before Thanksgiving. When I got home I walked into the house with my walker. I sat on the second step of the staircase. I stood up and my legs totally gave out. Did not see it coming and I hit my head on the floor. Luckily it was on the carpet. That is the only time in my life that I can remember just falling on the floor.

The kids helped me up and down the stairs for awhile. Wasn't long before I was doing it myself. Started doing some walking. On the day after Christmas I walked 4.3 miles. In January I continued with my physical therapy, which I had already been doing back in September and October.

I certainly have a new lease on life. It has been better than I thought it would be. I definitely want to live up to it. So now, the adventure begins.