

MY EXPERIENCE WITH ORGAN TRANSPLANT

By

Philip Perez

I was asked to write an article about my experience with organ transplant. First, I would like to say that I am very happy to share my experience with anyone, especially those who are going through or have been through the experience. My organ transplant was that of the liver.

I first found out I had this condition around 1986. I donated blood, and the place where I donated called me and notified me that I had this condition; and needed to go to my primary doctor for follow-up. When I went to my doctor, he ran further tests to confirm this illness. The medical community did not really know much about this illness at that time. They know it eventually attacks the liver, but because the liver is so resilient and strong, it takes many, many years (20-30 years) until a person develops symptoms. I figured I got this anywhere between 1971 and 1972 in the military because a few of my friends came down with the same condition who were in the military around the same time.

About 1992, I started to get tired easily. I was always strong--worked doing heavy physical labor, went to workout at a gym 6 days a week for 2 hours. My visits to the gym became less frequent and of shorter duration. Eventually, I could not go anymore. Some new medication came out, and I started taking them. The medicine made me feel even worse. I was on the medicine for a year with no success. Other types of medicine came out, and I was also put on them with no success. I was getting worse and worse. My liver was gradually failing me, and I was put on a multitude of medications to replace some of the functions of the liver. My memory failed me, I was extremely tired, and I became very swollen (legs, abdomen). There was nothing else that could be done. The only other option was a transplant. My wife is an ICU nurse and knows all of the ramifications of transplant. We had discussed this final option, and because I have two daughters and wanted to see them grow up, the decision was an easy one to make.

The next step in the process was to get a referral to see a Hepatologist at University of Miami, which we did. He did a few more things, and as I continued to deteriorate, he gave me a "laundry list" to see if I would qualify for the transplant. The list consisted of all kinds of tests they need (a word of advice to anyone going through this--make a copy for yourself of any and all paperwork). We got all of the tests together and gave them to the Pre-transplant Dept. Now, we had to wait for an appointment to meet with the Pre-transplant doctors to see if I did qualify. We never got the call.

I started to deteriorate rapidly at the end of January 2004. I was in the hospital 3 times in the month of February for a procedure called a paracentesis (where they drain

fluid out of your abdomen). As soon as they drained the fluid, it reaccumulated a few days later--this made it extremely hard to breathe as the fluid pushes up on your diaphragm. During this time, my wife called the pre-transplant people to find out what the hold up was, and to notify them that I was deteriorating very quickly now. They told her they did not have any paperwork except for a copy of an EKG. Thank God, she works at the hospital where I had all my tests. She made copies of everything and contacted our insurance company (as they also needed approval from them in order to be seen). Everything was taken care of within 2 days. I met with the transplant team and was approved for the transplant. I was number one on the list for my blood type (based on a scoring system they use based on your lab work). This status changes week-to-week. My status never changed, as my labs got worse and worse. After meeting with the Team, my wife drove me to my doctor who took one look at me, and admitted me to ICU. I was there about 3 weeks until a liver became available. I do not remember too much of my stay there--I was very close to death. I was on a type of dialysis that runs continuously (my kidneys stopped working), I was receiving nutrition through an IV, and I was receiving various blood products to stop from bleeding (the liver makes PT which is a blood product that prevents bleeding).

I was transported to Jackson Memorial on 3/18/04 about 1:00am. I do not remember too much at that time. Surgery was around 1:00pm. My wife told me that I got back up to their ICU around 3:00am the following morning, the surgery took about 14 hours. I was on a vent and sedated. I spent 2 days in the ICU. On the third day, I went up to the floor. I had to learn all about the medications I would be on, and signs and symptoms of rejection. I was discharged home on April 1, 2004. I spent 10 days at Jackson.

Recovery time varies from person to person. It depends on how sick you were before transplant, and how well your body is accepting the new organ. I know some people whose recovery was uneventful, and some people who never really fully recovered--they never were able to return to work. Recovery was difficult--I was bedridden for only a couple of weeks, but due to the lack of use of muscles, it was very difficult even to get up from a chair. There were a few occasions where I had to get friends to help lift me up off a chair. One time my wife had to call EMS to get me off the floor. It was difficult walking--I had to use a walker for about a month. I tired easily. I had a physical therapist come to the house a few times a week until I was strong enough to go to the Rehab facility. I had a nurse come to administer IV medication periodically. I was also dealing with the side effects of the medications--I was on high doses of steroids for a few months, which cause hallucinations and mood swings. I was also getting used to the antirejection medications which cause your heart rate to go up as well as blood pressure. I had to get lab work done about 3 times a week to monitor one of the medication levels. Eventually, the lab work was cut down. Now I only go one time a month.

I was able to return to work January 2005 on a part-time light duty basis, 4 to 6 hours a day depending on how I was feeling that day. Gradually, I was able to build up

my hours and now work 40 hours/week but I am still not able to return to my craft as a tractor trailer operator due to the medications I am still on. For me the recovery process is still going on. I am hoping to return to my craft in the future.

In closing, I would like to offer some advice to people who are going through this. First, I suggest that as soon as you find out you might need a transplant; you should try to get on a list. Go to your primary doctor and get a referral to see a specialist at a transplant facility to start the process. Second, when you are given the "laundry list" try to get all of the tests done as quickly as possible and always KEEP A COPY of all tests for yourself (just in case they lose them). Third, keep on top of the insurance company--this can cause a huge delay in care. Lastly, it helps to have someone to be your advocate. Remember, if you are going through this, you are probably feeling sick and there are many phone calls that need to be made.

For post-transplant, you need to be knowledgeable about the medications you are taking (side effects, dosages, times to take, labs and timing of lab work). I personally know someone who took the wrong strength of his medication (due to a pharmacy error in dispensing--however, he did not check the dosage, the pills even had a different color). He wound up very sick in the hospital and very well could have died. You must be educated in your care. Again, it helps if you have someone to help you with this--to double check everything, make sure you take your medication on time and get all lab work done. Make sure you follow up on your lab work.

Support groups are very helpful. The support group I attended was at Broward General Hospital. There was actually no support group there, and I helped to start one. We met once a month. The group was for both pre- and post-transplant. The post-transplant people were very helpful to those awaiting a transplant in explaining what can be expected.

I feel very lucky to be living in the age of modern medicine, and that I am able to see my children grow up and be there for them when they need me. For this I am very grateful. I want to thank the APWU for allowing me to share my experience with others. If you or anyone you know needs a transplant and would like to call me, I will be more than happy to talk to them.

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