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Subject: Islet Cell Transplant Experience
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Hi Dr. Witkowski,

I didn't know where to begin so I started from the beginning. Let me know if you have other questions or would like me to send some pictures. It was hard to put the events of something this big into just a few sentences...

In November 2013, my husband told me about a clinical trial procedure for an Islet Cell Transplant. After doing more research and discussing it with him, I decided to fill out the questionnaire. Within a few days I received a phone call from the nurse coordinator, Lindsay. I made the appointments to come into the office at the University of Chicago Medical Center to discuss the procedure further. The first day I met with Lindsay and Dr. Witkowski to discuss the procedure in depth and the medicines that would be needed daily post surgery. They both were very straight forward about the procedure and all of the IV drips needed the 7 days in the hospital. They mentioned that the 1 IV drip which is called Thymoglobulin could cause some pretty serious side effects such as severe headaches, nausea, vomiting, and diarrhea. They also mentioned that to get into the study I would need to go through evaluations of my heart, kidneys and liver; a lot of blood work was drawn as well. After all of the tests and sticks, I was put on the transplant list May 1, 2014.

On June 2, 2014, I received two calls. The first was a call from Lindsay around 11 AM telling me that today had a high possibility of being the day and to be ready. Around 3:30 I received another call from Dr. Witkowski telling me that they had a donor for me and could I come in that night. At 10:00 PM I was admitted into the hospital and the next day I began receiving Thymo. In order to receive the Thymo it had to be through a central IV drip line. This meant going through a vein in my right bicep to my chest. Other IV drips I had were a blood thinner, a clinical trial drug and saline.

On June 4, 2014 I had my Islet Cell Transplant. It was scheduled at 11:00 AM. I remember getting into the very cold room on the very cold surgical table. I remember someone say "And they're off" and I remember kind of waking up toward the end and seeing the x-ray screens. At around 2:45 PM (I think) I was back in a room at the Clinical Research Center being taken care of by Linda, Jackie and Reema. I was also begging for water and food. I had my insulin pump off for a few hours post surgery but eventually turned it back on at a basal rate of .3. When I left the CRC to go back to the room I would be in the rest of my stay I met with the pharmacist and Tiffany the Endocrinologist. We set my bolus rate of 1/50, meaning 1 unit of insulin for 50 carbs. While in the hospital I did not have any side effects except the Tuesday before I left I was nauseous, had a headache (would not call it severe) and lost my appetite. On Wednesday June 10, I had my glucose test; watching the numbers go up to 150 and back down to 110 was unbelievable. Before leaving I met with Lindsay, Dr. Witkowski and the pharmacist to go over my meds. They supplied me with a kit to help me keep track of everything. I was discharged June 10.

...the deep breath of everything. I was encouraged to see that...

Follow up appointments started right away being 2x a week for 2 weeks and then 1 a week for about 3 weeks and then down to every month. Every appointment they have to take blood work which consists of 5 to 15 viles. After every appointment I receive a call about changes needed to my med doses or to my insulin dose. I got down to .1 for a basal.

On July 25, 2014, my appointment gave me some surprising news. After being insulin dependent for 23 years, I was told I could disconnect from my insulin pump. For a few weeks after disconnecting, I would go to reach for my pump to give insulin when I ate, I would reach for it to check the time (time to get a real watch) and I would reach for it before getting out of bed. I carried it in my purse for a few weeks because it was hard to let it go. It is now November 23, 2014 and I am still disconnected from my pump and my numbers are consistently under 135 after a meal and any where from 100-117 fasting.

When I got home I had a few weeks of being very weak and shaky. I had a side affect to one of the meds called Difflucaan which made my heart rate high all the time. So far I have not seen any side effects of Prograft or Cellcept and next month (December 2014) should be my last month on Valcyte.

Through out the process, I have been very pleased with the support I receive from the team. Dr. Witkowski and Lindsay are accessible at all times. I enjoy going to the follow up appointments and receiving the blood work results. At one of my first follow up appointments I was told that my A1c was 5.2 just like a healthy person, this was very exciting to hear. Overall this has been an experience that I am thankful that I am able to be apart of.