Why I Returned to Life Technologies

Louise Lerminiaux Wellness Consulting LRL

Some people know I used to work at legacy Invitrogen in the eCommerce group from 2003-2006. After my transplant, I knew I wanted to be back in biotech to help educate and hopefully institute some change by sharing my experience on what works, but more importantly what doesn't work. Let me describe where I see opportunities from my perspective as a transplant patient.

Personalized Medicine

This initiative to help medical staff provide personalized solutions to illness is critical for the proper recovery of an illness. I started on 3 immunosuppressant meds and 10 additional meds to counter all the side effects. Right after transplant, the dosages are a pre-determined formula based on averages. They don't really take into account body size, prior health, what your body will tolerate or not. Every day, I got blood work to look at levels and adjust daily. On the day of my discharge, they had increased Prograf too much and it resulted in severe headaches. I don't get headaches so I was in a lot of discomfort. They gave me one pain med that I threw up instantly. Throwing up with abdominal surgery is VERY painful. I have an abnormal high tolerance for pain having done marathons, and this pain exceeded that.

They couldn't give me another med for a couple of hours until it cleared my system, so the headaches got worse. I was being told to eat and drink but I didn't feel like it. I was given a different pain med and threw that up soon after along with what I was being forced to drink and eat. The headaches persisted and I began to get dehydrated. A few hours later they tried another pain med and the same reaction occurred. After 14 hours, I was finally put intravenously on morphine to knock me out, and saline to get hydrated again. It was the worst day of my entire experience. I didn't go home that day as a result. The next morning I was much better but it was my wake-up call about the effect of these meds if the dosage was not just right, and the side effect risks I would face.

I mentioned how in my original post how it took 5 months to get the right combination and get down to minimal dosages. And I was faster than the majority because I was "healthy". During that time, I dealt with various side effects until dosages were manageable. There are still slight adjustments being made every few months depending on what my blood and urine samples show. I accept this is part of my life but to think that one day I could have some self-administered test or better yet, a chip inside of me that would automatically distribute the right dosage to keep my kidney from rejecting while minimizing negative side effects would be simply incredible.

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Stem Cell Research

There is no question that I would love to see a cure for PKD. Out of 6 siblings, my younger sister and I have the gene. Her daughter/my niece found out last fall she has it. She's 22 and had her own daughter 1.5 years ago. While I know my sister and I face similar predicaments with transplant or dialysis, I hope my niece (and if she has it my great-niece) have other options.

That's where stem cell research is critical. Until that time, there are also solutions to make transplants more tolerable and less risky, whether it is the ability to have one's one stem cells assimilated with a transplanted organ so there is no need to anti-rejection meds. There are transplants being tried today where the donor's bone marrow is injected in the recipient before the organ to also minimize, and possibly avoid, the need for anti-rejection meds. It is this type of technology that will enable people to live without dealing with adverse reactions of the meds. Unless you live it, it's hard to accept that the drugs I take 4 times a day to keep my new kidney will ultimately cause it to reject. There has to be a better way.

Electronic Medial Data Access

With all the great research and technology we have, there are still aspects that are so archaic. I had my surgery at UCSD, one of the top medical teaching hospitals. While there are computers in each patient room, there is still a huge reliance on paper. During my transplant hospital stay, I wore a wrist band that was scanned before each medication was dispensed to ensure I had the correct medication and the correct dosage. Even with this, they got my meds wrong sometimes; or they would not give me my meds on time because the scanner didn't work properly.

When I was doing the pre-op for my herniation repair surgery, I told no less than 10 staff about my current med regime. I was having surgery in the afternoon so I would need my Prograf upon waking, and then my CellCept a few hours later with food. I was reassured there would no issues as it was recorded on my paper and electronic file. The next day, I had my surgery around 5pm so after I woke from my surgery, I asked about my meds. I was told I need to move out of post-op first. I didn't have a bed ready for me on the transplant ward so I was put on an intermediary ward. I asked about my meds again and was told there was not record when they scanned my wrist band but they would look into it. I had my meds with me and told them I would take my own but they responded that would be a liability to the hospital.

I asked again in another hour and they were still trying to page a resident. After 3 hours, they still couldn't get a hold of anyone. I was told 'you can probably just skip it for tonight'. I told them that was not an option to put my transplant at risk and I would take my own. They finally gave me my meds at about 11pm but only had 2 of the 3 I needed. I got transferred to the Transplant ward later than night and again reinforced to the nurse I was missed Prednisone off the list and needed it in the morning. I was assured it would get added but again in the morning it was not and I went through a similar 'get my surgeon on the phone' fiasco.

I entered a formal complaint after my discharge with my surgeon and ward nurse of that staff. I explained how I was lucky to have been lucent and educated to push for what I needed but most patients are not educated; and having had surgery, would and should be resting and sleeping. The staff would have made an erroneous call to skip much needed meds to prevent rejection because the systems did not reflect it. They assured me their training would be updated regardless of the ward to impress upon the staff the need for life dependent drugs when dealing with transplant recipients.

The other frustration I have experienced is electronic sharing of patient data. Pre and post transplant, I get a paper copy of my labs because I want to know that I can do to help myself. I put them in Excel and watch my trends because there are correlations between my med levels, food I eat and the results. Today I get labs usually every 2 months with my nephrologist, and I have follow-up sessions with UCSD every 6 months. I end up bringing my homemade Excel charts to both because they don't have systems that can transfer data to each other, let alone trend it. My nephrologist is quite computer savvy and while he loves working with me, it frustrates him that I have to do the trending when a simple program could do this.

So these are some of the reasons why I have returned to Life Technologies – we have the ability to do so much to help solve complicated disease, and relatively simple problems like data sharing.