

Am I Just An Experiment?

Louise Lerminiaux Wellness Consulting LRL

In conversation with a fellow kidney recipient in the summer about his first transplant failure, he told me "you know, we are just experiments". I didn't like that reference at all. When I think of experiments, it's test tubes and chemicals in a lab, not my body because I have a transplanted organ. But reality is, organ transplantation is only 40 years old so meds and techniques are relatively new.

This experimentation aspect recently was validated for me. I've written previously about the med regime I follow consisting of Prograf (Tacrolimus), CellCept (Mycophenolate), and Prednisone. And I've also expressed my frustrations with the one-size-fits-all protocol, as they do not factor in body size, body fat composition, gender, activity level, diet, etc.

In the past two months, my Prograf levels have been unstable and my nephrologist cannot figure out why. We have analyzed everything....from the foods I ate, liters of fluid I consume daily, supplements I take, my antibody levels, vaccines I have had, viruses I may have been exposed too. But nothing concrete has come up. The only thing they could do was raise my med a few milligrams, draw blood, adjust meds based on results and repeat. This occurred every week over a series of 5 weeks. It's stable now but still no rhyme or reason as to what happened, and there is the possibility it will happen again.

I had a checkup 2 weeks ago with the UCSD Transplant team and met with their senior nephrologist Dr. Robert Steiner. When he saw what was going on, he too was at a loss, and asked if I would be part of a study to examine the effects of Prednisone. Today for transplant recipients it is typically prescribed with food but no one has ever studied if it would be more effective without food; or if it should be in combination with Prograf (vs in combination with CellCept). The standard is 5mg because it is such a hard drug but perhaps it should be more. Given I am reaching my 2 year mark and am petite, perhaps the 'normal' protocol just isn't the right one for me.

So this week I will be undergoing a form of personalized medicine. It's not what we as a company envision but I felt it was important to share so people can understand what forms exist today. I will be undergoing (2) 9-hour tests – one day 15mg of Prednisone with be taken with food with Prograf; and the other day on an empty stomach. Each day, I will have blood drawn every 2 hours so they can gather and trend data. The benefit is that while the study is for Prednisone, they will also be able to analyze my Prograf levels. And best of all, the results will be specific to me.

The ironic thing is Prednisone is generic, and no pharma wants to fund this type of research & analysis. Dr. Steiner is paying himself to conduct the study for (20) national transplant recipients. He has theories about Prednisone and wants to prove them. While UCSD can do the Prednisone analysis, he had to partner with a company on the East

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coast to develop the assays he needs to study the Prograf results. I asked him if he thought about using a local biotech but he commented no one wants to do this pro-bono. So that makes me question the partnerships we say we want to have with research universities, especially in our community. Perhaps it's not big enough or media worthy but in my little world, the results will create a regime just for me and ultimately prolong my transplant longevity, a much better alternative over dialysis.

I realize this still makes me an experiment but I see it now serves a bigger purpose – my results will help other recipients with my body type, and will help future research. So perhaps being labeled a human experiment is not a bad thing after all.