

I Guess I am Just An Experiment...

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I blogged in October about some challenges I had been having with my Prograf (Am I just an experiment?). This is a continuation of that blog as the study underwent at that time provided incredible value in the past two weeks...and here's why.

In Nov a few weeks after this study, I received an urgent call from my nephrologist. My creatinine was abnormally high and there was nothing conclusive as to why. I needed to cancel my next day flight to Pleasanton and get a biopsy ASAP. When one hears that, immediate thoughts are "Is the kidney rejecting?" "And if it is, how fast?". The biopsy while rather unpleasant revealed the kidney was fine, just inflamed from a really bad infection. I was immediately put on a strong anti-viral to rid it, and my Prograf was bumped up from 3mg 2x/day to 5mg 2x/day to get me back on track. We also realized a prescription I received from my general doctor 3 weeks before had a direct interaction with my Prograf. Unfortunately, I had taken the entire dose. We were optimistic my creatinine levels would settle down once the infection cleared and this drug interaction subsided, but it continued to creep as the months went by.

Two weeks ago in a regular checkup, I was told my creatinine was uncomfortably high again, and they could not figure out what was going on because the trough Prograf levels were in the right range for the past several months. I take 3 anti-rejection meds at 2 different 12 hour intervals. They typically only measure the end of the 12 hour period (also known as the trough) to see how much of the drug is left in my system to ensure no rejection. They wanted to do another biopsy and recommended I start plasmapheresis treatments since there were small traces of donor antibodies. The treatment was pulling at straws but they didn't know what else could be the cause. My nephrologist explained how I would undergo a series of dialysis like treatments 3 times a week where I would get hooked up to a machine to remove the antibodies from my blood. He thought I would need them for 4-6 weeks.

WHAT???!!! As I tried to absorb what was being said. I wanted a second opinion and asked him to call Dr Steiner, Sr Nephrologist at UCSD, who was part of my transplant team. As luck would have it, the Prograf results from his October study I had participated in had been analyzed (albeit 4 months later, Prednisone results still outstanding). It showed that 2 hours after taking Prograf, the peak levels in my system were 3-4x higher than normal ranges. In his 25 years of nephrology, he hadn't seen anyone with that level. He said between my small size and overall fitness, I likely absorbed it better than others. This however was causing slow toxicity ever since they increased the dose 4 months earlier, resulting in the creatinine rise, and if left undetected, possibly ultimate rejection.

Now we had a plausible cause and went about proving if it was valid. My dose immediately was dropped back down to 3mg, and we repeated the peak test 4 days later. We saw similar high peak levels, with a small decline in my creatinine. We were on to something. So to gather more trending data and hopefully see a continual decline in my creatinine, they asked me to do another peak test. I however suggested we take 2 back-to-back trough AND peak tests so we have 4 data points to compare. We need to ensure there is still some in my system at the end of the 12 hours to avoid antibodies attacking; while balancing not having it too high. They of course were thrilled at the suggestion since it's not the most convenient, but I want to get to the bottom of this as much as they do. I will get blood drawn this Fri and Sat and we'll figure out next steps once the results are in but they are very hopefully it is Prograf and will find the right personalized dose for me.

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I look at this experiment from a few different angles...I'm very fortunate to live in a community with access to top-notch transplant medical teams to get this personalized care. They of course are as frustrated as I because there is so little data on these immunosuppressant meds and transplants in general, but love that I am willing to be involved. But I think of all the other normal recipients out there who perhaps are in remote communities, less educated, may not have insurance or the income to undergo extra labs, may entrust their doctor entirely and never take an active role in understanding their condition, asking questions, asking for other opinions. If I didn't do the latter, I would have a catheter in my neck right now and be in plasmapheresis treatments this week.

There has to be a better way and I believe the initiatives LifeTech has towards personalized medicine is part of the solution. Sure I would love a cure but I'm past benefitting from that. As long as I have to take these drugs, it would be better if there was some chip inside of me, or some quick blood test I could do at home, that would automatically detect when levels are too high or too low to avoid getting blood drawn and then waiting days, weeks, months for results. The time in getting the results back from the study are probably quick by some standards, but 4 months can be the difference between life and death for some patients. I've also questioned my medical teams whether they will be adding peak, along with trough tests to their patient regime and they likely will because of my case until something more automated is available.

The drug interaction mistake by my family doctor was because she didn't manually check a box to see the extra screen that showed drug interactions. A common mistake I imagine happens more often than not, and one she felt horrible about. We discussed it at length because fortunately it wasn't detrimental to me, but it could have been or another patient. We agreed going forward, she and I will consult with my nephrologist before prescribing anything. Why can't systems automatically display this information based on patient data vs expecting a physician to check a box? Why can't she, my nephrologist and UCSD transplant teams have all of my data electronically shared so there are several sets of eyes especially for complicated illness to avoid this? Why am I as the patient asking for paper copies of my labs, trending them myself in Excel and giving copies back to these 3 teams because they don't have integrated software programs to do this?

I have accepted I need to take responsibility for my own care to the degree that I can. And I also accept this type of rollercoaster and continually med adjustments is my norm. We however have the talent and the expertise to help those who are not as fortunate, today and in the future.