

Update on my journey with Essential Thrombocythemia



Oncology/Infusion Clinic at Kaiser Redwood City. The "EXIT" sign at the end of the hall seems symbolic yet wasn't noticed when I took the photo this morning.

Why. Not that there's an alternative, but that first time I met with my Oncologist/Hematologist, and you're in a part of the facility you'd never been before, or maybe you walked past and saw gaunt, pale people, generally a lot older than yourself, usually with someone else who'd driven them. You had maybe lost a family member who'd been taken care of in this part of the hospital. And now, without warning, you are there. Why.

On my first visit, I didn't pick up on much, because I was so, well, scared. Yeah, I know, guys aren't supposed to be scared. But I was. In a period less than 24 hours I'd gone from having a blood test to confirm an anomaly to emailing my GP about the results to having an appointment with an Oncologist the next morning. No time to intellectualize anything or pay attention to my surroundings. I was in a place I was scared to death of being.

That was just over 6 months ago. Since then I've gotten past my severe, primal-fear sort of thing over having blood drawn. A weekly blood test didn't give me much choice.

Now, on my third visit with my Oncologist, I begin to notice things. The Oncology/Infusion clinic is the last department in the wing. Only an exit door beyond. I didn't attach any symbolic meaning to the exit sign when I took the picture, but now...



Ironically, it seems to have taken a chronic illness to cure me of my white-coat blood-pressure-spiking syndrome!

The nurse that took my weight, blood pressure and history. Whatever I said, she looked for a way to be nice and reassuring. I didn't

need a lot of empathy today; it seemed almost out of place, wasted on someone not that bad off. Where was she on my first visit, when I was terrified? Maybe she was there, and I was beyond reach.

Looking back upon my admittedly-brief journey so far with my mild chronic form of bone marrow cancer, it's that first 10 days post-diagnosis that stand out, that will always stand out as a soul-searching, potentially life-changing and exceptionally frightening experience. The only remotely-similar time in my life was when my son had his first major seizure and I'm at the hospital watching the doctors spend two hours trying to stop his convulsing, and in two hours an awful lot of possibilities go through your mind.

Today, exactly 7 months after the first test showing something screwy, I'm in a very different place. I find myself in a sort of competition to get my "numbers" (blood values) to a better place. I've come to understand the contradiction of a disease that's incurable but can be managed. I have moved from my disease defining me to me defining the disease. I have even made progress on my "white coat syndrome" where I would spike my blood pressure on a visit to the doctor.

There remains one major, future-defining test, coming up sometime in February. That's when I undergo a bone marrow biopsy, the only way to find out if my bone marrow issue shows elements of morphing into something that can progress beyond chronic, making mortality issues as real as they are feared. If you feel fine (which I do), do you really want to know? But in the worst-case scenario there are choices to be made, and risky treatment options (stem-cell transplants) that could make sense but would be crazy to consider now.

I am, all things considered, in a pretty good place. In a bizarre way I can say that I have my health, given that there are few limits on what I can do, and I likely remain in better shape than most people a bit younger. I have a great family, I have found support and solace in two groups for people with Essential Thrombocythemia on Facebook ("Essential Thrombocythemia" and "Essential Thrombocythemia Support Group"), I have "remembered" my faith in God I have greater appreciation for the trials faced by others.

My daughter Becky, reading this, thought it was a bit morbid and depressing, especially considering that I'm responding wonderfully to my medication and it would really be tough to have better results than my tests this past Friday showed. My doctor's appointment went very well too, as she noted there is no longer any enlargement of my spleen. I am virtually symptom-free; I could not ask for a better place to be than where I am right now. But that doesn't re-write the story; this is about how I got to where I am, and where I am heading.

The plan (remember, there's always a plan) is to live long enough to definitively prove that you can literally bore people to death by repeated ramblings like this one. That will be tough to prove without being around for a very, very long time. That's the plan. :-)
--Mike--