Cancer Health™

Frustration Gone Rogue

Facing testicular cancer during *Star Wars* month was a double-edged sword for this super geek, just like Darth Maul's lightsaber.

December 26, 2016 By Justin Birckbichler

Star Wars: Rogue One came out about a week ago (as of this writing). I am a movie fanatic and love seeing movies on opening night. There is a certain electricity in the air when a ton of ~~movie fans~~ geeks gather to see a new movie for the first time. I absolutely insist on seeing all the Marvel movies on opening night.

But things are different now. I missed Rogue One on opening night. While I'm not as strong of a fan of the Star Wars series, I still love discussing movies with my friends, and I felt a little left out. On Twitter and Instagram, I saw many of my friends posting pictures of them in the theatre or sharing brief (and spoiler-free) reviews. This may seem like a silly and trivial thing to be upset about, but I also had a number of weightier issues on my mind.

I've got a bad feeling about this

As I said in "Losing My Hair, But Not My Control," my white blood cell counts dropped the week of December 12. I was tested on Monday (with a score of 0.65), Thursday (0.35), and Friday (0.44). Seeing that my cells rebounded between Thursday and Friday made Nurse Practitioner Candace and Dr. Maurer optimistic that they would continue to rise over the weekend. If they didn't rise to 1.0 by Monday, December 19 (the start of my long week of chemo), I wouldn't be allowed to continue treatment.

The 19th arrived and my blood was drawn. About fifteen minutes later, Nurse Jenn came back with a grim look on her face. My cell counts hadn't risen. They hadn't even maintained. They dropped back down to 0.35. I wasn't allowed to have treatment this week. I was beyond disappointed in myself and my cells. While I wasn't expecting my cells to rebound completely, I didn't think they would drop again. I kind of sat there in a stunned silence when Jenn told me.

A darkness I sense in you…

To be honest, I was very frustrated throughout the past week. Not being allowed to have treatment moved my entire treatment plan back a week. I never thought I would be upset about chemo being pushed back, but it represents more obstacles. I'll also have to have part of my new cycle in an unfamiliar infusion center, due to my normal office being closed for the holidays. Moving everything back also represents more time off of work (and more time unpaid, which is not something I need when I have bills pouring in).

On top of not getting treatment, I've had a number of general frustrations since my last round of chemo. I'm not allowed to do anything or go anywhere, because of the risk of infection. I just have to putter around the house, watching movies, playing video games, and resting. An ideal weekend yes — but this has been what I've been doing for the past few weeks. My strength isn't quite high enough to go on walks, and I also don't want to take an unnecessary risk.

I was planning on visiting my students before Christmas break, since I haven't seen them since before Thanksgiving. Obviously, with my cells down, there's no way I could be near students, since an elementary school ranks somewhere between biological weapon and petri dish when it comes to risky germ exposure. I recorded a video message for my kids, telling them how much I missed them, wishing them a happy holidays, and showing off my shiny dome. Though I know they appreciated the video, it still wasn't the same as physically being there with them.

Another downfall of my falling cell count is that I've had to limit my exposure to my fiancée. Mallory and I have had to sleep in separate bedrooms and staying apart in general, since she had a cold a week ago. A minor cold for a normal person can become a life-threatening episode for someone with a compromised immune system, so we decided to be proactive. Still, having Mallory next to me as I sleep has always been a comfort, even if she is a covers hog. This separation, coupled with the general restlessness that is a side effect of my chemo, means I haven't been sleeping well in general, which is another difficult thing to deal with.

Probably the most frustrating thing is that I can't do anything to raise my cell counts. My medical team will give me neupogen (a marrow growth factor) in my new cycle to help prevent this from happening in the future, but they want my cell counts to replenish themselves first. There's nothing I can eat or do to help stimulate cell growth. This bothers me a lot. I like to be in charge of everything. Knowing there is nothing I can do to fix this is hard to accept.

I'm aware that my issues are still mild compared to someone in Stage IV who is in chronic pain. Still, despite my positive attitude that I strive to keep up, I'm frustrated. I feel like I've done everything right along the course of treatment. I've been limiting activity to let my body rest, eating a balanced diet, drinking tons of water, downing bottle upon bottle of Vitaminwater and Ensure to help replenish nutrients and electrolytes, and keeping up with all my meds. None of this seems to have paid off. My treatment course is very aggressive (since I have an aggressive cancer), and it's taking a physical toll on my body.

Please, Nurse Jenn, you're my only hope

As I walked into the office on Thursday, December 22, to have more bloodwork to see if my cell count had raised, all of these frustrations were weighing on me. I was sure my counts wouldn't be where they needed to be. There were four days between my last two checks and that time, the levels dropped. It had only been three days since my last check, so I wasn't expecting much. I really didn't think my counts would raise much past 0.65.

The blood technician came back holding a sheet of paper. She handed it to me and I quickly scanned it. I was right — my levels weren't at 0.65 or even 1.0. They had raised all the way to

1.87.

Words cannot describe how happy I was. Finally, after nearly two weeks of things not going right, there was good news. I immediately asked to see Nurse Jenn to ask a few follow up questions. She came out of the infusion center and said, “I heard your levels are up and you have some questions.”

“Yeah, I really just have one main one. Can I—”

“Yes, Justin. You can see Star Wars.”

It’s funny how quickly she had gotten to know me. I asked her to voice record her permission on my phone to prove to Mallory that we could go. I got home, played the message, and we made plans to see the movie at 2:30 that afternoon.

Even though my immune system wasn’t compromised anymore, I still wore a facemask to the theatre as an added precaution. It helped me bring out my inner Darth Vader. (Although, with a bald head and face mask, I looked more like Bane from The Dark Knight Rises.) To be quite honest, Rogue One was a bit of a let down, but ABSOT isn’t a movie review blog nor will I get into spoilers here. More so than being able to see the movie, I was most excited I could get out and do what I wanted to do…for once.

Much like for the Rebel Alliance, things were now looking up.

A simple white blood cell count of 1.87, along with a plan to resume treatment on December 27, renewed my sense of joy and positivity, which I was greatly struggling with prior to this. The frustrations that had been gnawing at me all week quickly faded into the background with the resurgence of good news.

As we headed home from seeing Rogue One, the positive vibes kept buoying my spirits. Christmas and New Year’s were just around the corner, and I was ready to celebrate the holidays with my family.

I’m currently undergoing chemotherapy to cure my cancer. Each Monday, I’ll post my thoughts on this experience. These may be reflections on my prior week’s treatments, musings about my newly-altered life, or anything else that comes into my “chemo brain.” Follow along with all of my posts here.

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