

Wallowing, Advocacy and Waiting

Despite the return of my lung cancer—and stressful lab situations—I remember how fortunate I am and I look to the future.

February 2, 2023 By [Dann Wonser](#)

Friends and Family,

There should be another stage of grief, the first stage, called wallowing. That's what I was still doing when I wrote the last story. I've gotten past that now, and I'm again remembering just how fortunate I am to even be here. I'm looking to the future again.

We don't have a clear direction yet, but we do have progress. We were also reminded of the importance of being your own advocate.

Monday morning the hospital scheduler called and said that my records had been sent out to the clinical trial sites and that I had a biopsy scheduled for early Wednesday. So far, so good, right?

I reviewed the MyChart note from my last oncologist appointment to see if I had missed anything. The note included an update from the lab with a FedEx tracking number for my blood biopsy, so I followed up on it. The number was faulty.

Genevieve and I talked over how to track down the problem in a big hospital system, then I left my nurse navigator a message and crossed my fingers. Without the biopsy results, we don't know what treatment will work for me.

That afternoon the scheduler called to say that a diagnostic imaging tech had cancelled my liver biopsy because there was no order to stop my blood thinner before the procedure. It didn't matter that I had already stopped it - the order had to be in the chart. By this point our stress levels were mounting, and all our "stay in the moment" mantras were failing.

The last time my cancer started to grow it spread like wildfire, and we are still traumatized by the memories. Now I'm off chemo, so the cancer is growing faster. I called my PCP's office and gave my best impression of a hysterical patient with that story. She said she would fix it and call back.

Several tense hours went by before a different diagnostic imaging tech called to give instructions for the Friday biopsy. I told her I was holding out for Wednesday, then gave her my hysterical patient story. She took the call to action and called my PCP's office, got what she needed, then called me back with a Wednesday appointment. It took advocating for myself and one

compassionate person in the right place to solve the problem and prevent a treatment delay.

Next, my nurse navigator called. The lab found my blood biopsy in a refrigerator and put it out for pickup with a new tracking number. My oncologist was notified of the error and the nurse navigator submitted the event for a critical incident review. Given the mistake had already happened, it's the best outcome we could hope for. The sample arrived Wednesday, so we'll have the results in a week.

Also on Wednesday, I had my liver biopsy. But just before it started, I learned that this was the diagnostic imaging tech that had been the barrier to my appointment. I calmly articulated the impact her actions could have had on my cancer and the stress they caused for Genevieve and me. She told me how busy she was. When the procedure was over, I was still under conscious sedation from a drug which causes you to forget most of the procedure. Still, I made sure to remember what came next. I stopped the transport person from wheeling me out of the room until I told the diagnostic imaging tech that I wished that she had used the time she spent canceling my Wednesday appointment to call my PCP's office and solve the problem. She was still defensive, but she heard me. I can only hope she'll think about it the next time she's in that position.

It looks like at least another week before the blood and liver biopsies are in and we have all the trial information. I'll keep you posted.

Love,

Dann

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