

Fireworks, Bureaucracy and Cancer Clinical Trials

What makes an excellent oncologist? Lung cancer survivor Dann Wonser offers seven criteria.

June 22, 2023 By [Dann Wonser](#)

Friends and Family,

We got the scan results last week from my latest CT. Anyone with cancer knows that no matter how good you feel, you can't always tell when the cancer is on the move again. I was feeling good, but still not confident we were going to hear the magic word, "STABLE."

And we didn't.

Instead, the cancer had shrunk again! We're still smiling, a week later. Cue the fireworks! No need to wait until the Fourth of July!

Now I'll tell you what else we've been up to. I was ready to schedule a flight to Denver to get into one of four trials at University of Colorado when I got into the amivantamab subcutaneous trial in my hometown of Portland. Even after I got in, Genevieve and I flew twelve hundred miles to sign informed consents and have my tissue biopsy tested in Denver. Why would I do that when I was already in a new trial? Because we didn't know if amivantamab would work, or for how long.

I'm glad we did it. I'm four months into this trial. But if had not worked, or if it stops working soon, starting over takes time. That time can be life-critical once the cancer starts growing.

This will show you how critical time can be. It takes a week or two to get an appointment in Denver. Once I had the appointment and signed their consents, it took more than a week for the hospital to request my tissue biopsy be sent from Portland. It then took another three weeks to find out that I didn't qualify for any of the four trials. That means it would have taken five or six critical weeks while my cancer was growing to find out I didn't qualify and would have to start over elsewhere. I'd like to tell you that the bureaucratic delays I experienced are rare, but I have run into the same kinds of issues in two other hospitals. I'll spare you the details, but it took two months from when one oncologist told me he would order a liquid biopsy to the day I received results, even though I was prodding every day to keep the wheels turning.

In the future if I need a new trial, I already have a foot in the door in Denver. This will hopefully cut weeks of delay out of the process when timing becomes critical and I'm trying to stay alive.

A huge factor in all of this is your oncologist. Here is what I think makes an excellent oncologist:

1. THIS IS THE MOST IMPORTANT THING: THEY NEED TO BE A LUNG CANCER SPECIALIST. I have had seven oncologists, and the two that almost got me killed were the only ones that were not lung cancer specialists.
2. They react quickly. As soon as your cancer shows progression, they order a new biopsy. (Always get a new biopsy!) As soon as the biopsy results are in, they search for treatments that are a fit.
3. They collaborate with you. You discuss the options together and make a plan. This may mean that they call you and not wait for your next appointment. Time is critical!
4. They are open to clinical trials. Every survivor I know with active cancer that has lived for at least ten years has been in at least one clinical trial, and some have been in six or seven! I'm on #3.
5. They strategize when to stop your current treatment. If you are entering a trial, that trial will have a "washout period," which is the time you must be off your old treatment before starting the new one. If they discontinue your old treatment but it takes six weeks (like my Denver example) to get into a new trial, your cancer could be going wild. You want to remain on the old drug as long as possible before starting the new.
6. They make contingency plans. Ask your oncologist, "What do we do if this treatment fails?" and don't let them leave the room without giving you an answer.
7. They really care. Nothing has made me feel safer than hearing my oncologist say that even if I was in a trial somewhere else, she would always have my back.

I'll get off my soapbox now. I hope treatment is going well for you, and if not, that you have a plan of attack.

Love,

Dann

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