Change of Plans

This is not the story I had hoped to write.

October 30, 2021 By Dann Wonser

After my first week in the new clinical trial for BLU-945, my cough had decreased and my breathing was easier. It seemed like a no-brainer that things were going to keep getting better. I had fantasies that this drug was The One. As in, the one that got rid of every bit of cancer and left me with no evidence of disease (NED).

But that's not how it turned out. Even from the beginning, there was one trouble sign. The pain in my back flared up during the one-week "washout" period, when I had to go off Tagrisso before I could start the trial med. It has been getting worse, to the point where calling it a nightmare is not an overstatement. I am grateful that my oncologist responded to the severity of the pain, but it escalated faster than we could get new scripts authorized by insurance. The other issue was a pharmacy that thought I was a drug addict and put up barriers. For this last prescription, paying pay out of pocket while awaiting insurance authorization wasn't even an option. Fact #1: I WAS drug seeking. Fact #2: People in severe pain can look just as desperate as drug addicts, but it doesn't mean they should be treated the same.

The other surprise was that in the two weeks since I wrote about the wonderful improvement in my breathing, I am now panting hard for minutes after doing nothing more than getting into bed.

Fortunately, I switched to a new local oncologist to help with the things that need to be handled in Portland, such as scans and Xgeva shots. Even better, she and Dr. Padda are friends. The two have worked closely to problem solve. As a result, I have had multiple tests in both Portland and Los Angeles in the last week, which has clarified a lot.

First, an MRI showed that seven of the lower eight vertebrae in my lumbar and thoracic regions have cancer, which is the source of my pain. The cancer swells the bones, which then press up against the nerves in my spine and cause pain. I'll be starting radiation treatment to address this as soon as the radiologists work out a plan.

Next, a CT scan and echocardiogram show that I do NOT have a new pulmonary embolism (whew!), but I do have fluid building up in my lungs and around my heart. This explains the breathing difficulty. I will have that fluid drained off as soon as the procedure can be scheduled, and I should breathe easier again. Is it weird to look forward to a needle in my abdomen?

The CT also showed that the cancer has expanded in my liver, but so far my liver function tests

remain normal. The last thing the scan showed is that there has been some improvement in the cancer in my lungs. Dr. Padda believes that the BLU-945 is working on some mutations but not others. There is also a question of whether a higher dose would make a difference, but Phase I of the trial, which I am part of, is about determining what dose can be tolerated, not what dose is effective. My dose can't be adjusted.

For those of you wondering if BLU-945 might work for you, keep in mind that I have EGFR but do not have T790M or C795S mutations, which are the primary targets of this treatment. None of my experience applies if you have those mutations.

Not surprisingly, I am out of the BLU-945 trial. In the short term I am back on Tagrisso until the next step is in place. Last week Genevieve and I talked with my local oncologist, Dr. Sanborn, about potential next steps if I washed out of the trial. We are in agreement that I will go back to chemo, possibly along with Tagrisso. The Tagrisso is clearly doing something. Research in the last several years shows that chemo is more effective after radiation, so I may be on Tagrisso by itself until radiation is done.

Our friend Donna was on Tagrisso for just two months before it stopped working. Her doctor kept her on it and added chemo. Remarkably, on that combination she now has no evidence of disease. We're hoping that I will have the same outcome, though we would settle for a lot less. ????

Thank you for all of your love and support through what has been the most challenging time in my fifteen years with lung cancer. Even when I have been too overwhelmed to respond, your words and acts of kindness have meant everything to me.

Love,

Dann

This post originally appeared on Dann's Cancer Chronicles on October 23, 2021. It is republished with permission.

© 2026 Smart + Strong All Rights Reserved.
http://beta.docker.cancerhealth.com/blog/change-plans