Clinical Trial Month 21 of 24 ... Ibrance

The decision to sign up for a clinical trial is not easy; there are risks for everything we do in terms of health and wellness.

March 20, 2019 By Lisa Vento Nielsen

I have been very remiss in updating about my clinical trial experience taking Ibrance the stage 4 breast cancer drug despite being an “early stager” (Stage 3A with old staging, 2B with “new” standards of staging — no I was not restaged but I did research it and like to bring up the differences of the staging guidelines in the timeframe of a year and change from my initial dx).

At this point, I am almost done with the trial — which is just mind-boggling to me. So, as we know from my experiences on my pilgrimage, I believe I am cured by Saint Padre Pio who continues to advocate and heal people. While on my pilgrimage many things became clear to me, including the decision to continue with the trial despite I guess having some say, “Why not drop all the drugs and just live” but I will continue with my hormone suppressor and my clinical trial anyway because it cannot hurt and the trial is almost over…

I am currently in month 21 and almost ⅓ of the way done with this month. There are just 24 months in total. Despite the side effects being multiple pages long, I have been quite lucky and have tolerated the drug at full dose all of these months. I just want to keep knocking on wood and saying thank God.

If I run a fever, I need to go to hospital. I have taken two trips over these last 21 months for full complete bloodwork, chest X-rays and the works just to be sure the fever was not caused by an underlying infection that my body could not fight due to the suppressed immune system that is part and parcel with an inhibitor pill like Ibrance. I am actively thanking God right now that I was able to go to Europe and continue to live without having to go to the hospital — I hope this streak can continue til the trial ends (prayers welcomed to help me do that!).

I also have found that I am tired but I do not truly know if this is from the meds or just my normal tiredness as I think I was born tired. Through the trial, I have had multiple follow ups — much more than the normal “life after cancer” routine. I have had appointments in the beginning of the process every two weeks — blood work one visit, oncologist appointment the next two-week session, with pills being given to me for the month only.

By month 3, this changed to once every three months with bloodwork and oncology visit combined. In addition to these appointments, I also needed to do my three-month Lupron shots (until I removed my ovaries in November 2018) and of course that appointment never lined up

with the clinical appointments so it meant two visits every three months AND surgical follow up every six months (which I just graduated from this past December; though I still have my yearly mammo and ultrasound on the remaining breast each December).

So my post-cancer-treatment phase has still been full of appointments, checks and that connection to the hospital and staff. There was no abrupt break up so to speak. For some, this might be a terrible thing but I felt it helped me cope and continue to move forward before I had confirmation that I was cured to believe that I was anyway.

The decision to sign up for a clinical trial is not easy; there are risks for everything we do in terms of health and wellness even before we become cancer patients. Just taking a Tylenol comes with tons of warnings and side effects that my surgeon pointed out to me that if we read the warnings, we would not even take that for a headache. Were you offered a trial? Did you decide to take part?

Since my Ibrance trial, I have also taken part in the Fit2Thrive study which measured and encouraged physical activity for cancer survivors, a study on intimate relationships and fertility post-cancer (obviously, the fertility was not a requirement for me as I was lucky enough to have children before hormone-positive cancer) and also a recently acquired hereditary study where I will be re-screened for genetic components for cancer despite already having done a screening in 2016; so many things change that it is important that I get another chance to have this screening done.

So did you take a trial or sign up for a study? Why or why not?

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