



Victorian Cancer Trials Link

Clinical trial participant, Ilka Carapina, shares her experience of being treated in a cancer clinical trial.

My name's Ilka Carapina and I had a stage one ovarian cancer diagnosis in the setting of having surgery for endometriosis.

What led you to participate in a clinical trial?

At my first visit with the oncologist, I was given options about receiving treatment, including chemotherapy. My oncologist also told me that, due to certain parameters, being in the right age group, being the at the right stage of my cancer, that I was eligible to do a clinical trial.

What information were you given before deciding to participate in a clinical trial?

Before deciding to participate, my oncologist explained what the trial was trying to achieve and gave me some reading material to take away. The reading material consisted of a layman's statement – a summary of the trial that any person could understand, including information about the study details. There was also the consent form.

When my oncologist explained the trial, she didn't push me either way. She was telling me what the trial was trying to achieve and also what the benefits were to individuals. She didn't push me. She did encourage, presented all the facts and that's all you do – you look at the



facts. She did explain that there might be some side effects. She went through them and, to me the risk of the side effects versus the gain I felt was enough for me to proceed on the trial.

Did you have any concerns before consenting to participate in a clinical trial?

I think the main fear I had with going on a trial, because it's a trial, in essence it's untried for your particular circumstance. So, the drug I was on had been used for other cancers, but not for ovarian. I had a feeling that they wouldn't have extended it to another group of people if they didn't think it was going to have some use to them, but my biggest fear was the side effects and whether they had managed to map all of the ones that could be as a result of this drug.

Did you encounter any challenges on the clinical trial?

Approximately around the six month point of being on the clinical trial drug I started to feel that the side effects were building up.

I went and spoke to my oncologist at my next visit and I told her that I wanted to drop out of the trial. It was getting too much for me and she was good about it. She wasn't wondering why I needed to do that because she had been hearing about my symptoms at my regular check-ups. The nurse was the same and once I finished on the trial I still ended up having follow-up. My regular follow up, plus the follow up from the clinical trial.

If I had the opportunity to go back in time and was reoffered to do the same clinical trial, knowing what I know now, I still would. I still feel the benefits outweigh the side effects.

What were your main reasons for participating in a clinical trial?

I've thought about the reasons I got into being in the trial and they're still the same. It was personal benefit, or personal gain. I wanted to make sure I had received all the treatment I could and I felt I did. But, then there was also the other part of it, that I didn't have to be on a clinical trial, I chose to be on a clinical trial. I had all the information I needed and all I could think about was all the women who would go through what I went through and try and make that journey for them much easier.

So, trying to get less people to go through what a smaller group have so that the greater group doesn't have to.

To watch a video of Ilka explaining her experience in full, visit
www.cancervic.org.au/trials.

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and The Ian Potter Foundation.

