

Annette: The Importance of Self-Advocacy and Researching

Then we found out it was Stage 4 and my husband passed out again. He's not very good. So he's in the bed where I was. He just went over and laid down in the examining bed. That's when the real research started and that's when we realized that we need to really do something about this. At that point we kind of felt like the medical system had let us down. That there wasn't enough happening around this and we'd already knew that it was Stage 3. So we started doing a lot more-- Raymond started doing a lot more research. I still had not looked at the internet at this point. I still haven't, to be honest, I've never looked at the internet on what melanoma has to say-- nothing.

I've never looked at anything. He showed me--when he found the immunotherapy that was still in testing at the time when I was diagnosed, it wasn't a standard treatment. He's like "okay, you can look at this one research." That one they had 47% survival rate and that was the best that we could get at that point. So he's like, "you need to read this. These are the drugs that you need to get 47% survival rate. This is going to be you. So this is where we're going. This is what you're getting." So we kind of knew that the medication was out there. We knew somehow we could get there. That's when we started going to Alex. So that was a game changer.

I think all the way along, everyone that we talked to, they all said, even Dr. Smiley said "just be the squeaky wheel be the squeaky wheel, make sure you're this squeaky wheel." And we were like, the squeaky wheels need to ask for something and we don't even know what to ask for. I don't know-- how do you be a squeaky wheel in this world of oncology and BC Cancer? So I think part of what Alex really helped us with was knowing what to ask for. Knowing what was out there and knowing the different paths that we could go. He gave us lots of things. He explained the cancer to us. So we finally understood it. For me I think that was paramount because I then could take everything that he was suggesting around diet, about exercise, about all those things, about relaxation, trying to de-stress, trying to get your nervous system calmed down, trying to get your inflammation down. All those sorts of things made sense to me.