Interview with Victoria Fonsou

Transcription

I am a Victoria Fonsou, from Greece. I am a breast cancer patient and also a caregiver of my father, who has just been diagnosed with colon cancer.

In order to survive, I self-educated myself, and for the sake of my father also. I keep myself updated in research papers and guidelines and best practices. In daily practice I search through the internet and translate everything I find useful in Greek for my peers and myself, and I use the social media to disseminate this knowledge.

Searching through the internet all these years — I'm a patient for the last five years — I realised that I needed a service, an application, that I couldn't find. So, last year, since last year, I decided to develop it to try to develop it myself.

It is a social platform, and you have a profile, you have to sign up and make your profile, and you are in the moment a member of our society. It is a safe social platform and is about … Our data is our own. This is the main thing.

They can find like-minded people all over the world, in a safe environment.

My idea is mostly about the recently diagnosed, the people that don't know nothing, like all of us, because nobody of us knew anything in the start. You are … You lose everything, and you don't know anything. I mostly target to them.

They will find to whom they should be connected to. I believe this is the most important thing. When your life is threatened you don't have time and you need answers right now.

I don't know nothing about coding, and I should know to develop such a thing. I tried for many years now to build something by my own self in the web, with the free web tools. I tried to make, to build a forum. I have in the start, I have made many things in Facebook and social media and all ways, but that was not enough. It was not the set that I would like to have, and about eight months from now, back, I decided to learn coding myself. I started, I realised that I can not do that all by myself, because I want to do it fast, so I started pitting my idea in conferences and universities and people, and I found a professor of University of Athens hear to my project, and he said, "I will help you," and he introduced me to his team of colleagues. By that time I had also found out by myself an application that I could use to develop my platform, and I had a prototype. That was the way, how the people came to me.

I believe that if you have the best environment to communicate and connect patients, patient organisation, projects, then our impact as patient advocates will be accelerated in the maximum way.

WHAT ARE SOME OF THE CHALLENGES AND BARRIERS THAT YOU ARE FACED WITH IN YOUR PATIENT ADVOCACY WORK?

The number one barrier is the language. I read, I search, I do everything in English, and I also translate them into Greek. It is both time-consuming and difficult. In Greece we don't have an established health technology assessment body, so I am a knowledgeable patient who everybody stares at, but nobody knows what to do with me. I feel a little like alien in my country. We are not in that level yet.

I believe in education. It is a long distance run, and only time can prove its value, our impact. Having said that, I know that life can't wait. As a patient, I know that. I seize the opportunity to act right now with this application. Yes, we are in the start, but I'm willing to try it.