

Interview with Diego Villalón

Transcription

Well, my name is Diego, Diego Villalón, I had lymphoma when I was 23 and since then I've been involved in patient... In different patients organisations. Two years ago, with other patient advocates, we founded MÁS QUE IDEAS Foundation. This is a non-profit organisation, that support patients organisation and also it serves like a hub for the different stakeholders that contribute to the quality of life of patients. Our aim is to improve health and quality of life of patients, so we are very committed with the health not only of people that today are living with a disease, but also with the people that, in the future, that will have a disease, that's the reason we are committed with the research.

My motivation comes because I had cancer, so the prognosis was really well, was really positive and that's because the great advances of the research, of the drugs in lymphoma. So I'm really committed to help the researchers how to get better drugs only... Focus also in quality of life, because it's really important the efficacy and safety, but we also to think about quality of life issues. So I think the patient advocates can help to contribute in that way and also to work like other stakeholders so important in this process of the medicine research and development.

I'm currently involved in a project of the Spanish Health Minister that we are creating like a methodology document to identify how patients can involve in health technology assessment. In Spain we don't have any national HTA, but we have many regional HTA, so it's important to provide a document to help them how to include patients in this project. So we are now currently developing this project and we are

happy about that. Also, I have the opportunity to be member of different advisory boards and for pharmaceutical companies, about different research issues, like for example, information leaflets for patients and also the lay summaries, so important right now. And now we are also developing a project to develop leaflets and other educational materials about bio-banking, that also we consider really, really important.

HOW HAS THE EUPATI TRAINING HELPED YOU WITH YOUR ADVOCACY WORK?

Most of my knowledge and capabilities about research came thanks to EUPATI course, it's amazing, but I think that the face-to-face meetings as well as the online seminars, webinars, also the modules of the course helped me a lot to have better knowledge about these issues and also it inspired me to... motivating me more to know more about this topic and now for example, I'm reading a lot of articles, guides that I find on internet. So I think that to be a better, a good empowered patient advocate working in research, I think that it's really important to learn also by ourselves, and also work very close to the researchers that they can teach us how to do a real change in research, and to help to change some protocols, and to do it more adaptable to the patient's reality.

I invite everyone to involve in patient advocacy especially in research. I think that there are a lot of things that we can do and only we can do it if we are together, that we are strong and also try to get evidence, evidence to know that our voice makes stronger and the authorities can listen to our requirements.