

Interview with Souzi Makri

Transcription

My name is Souzi Makri, I come from Cyprus. I'm an expert patient, I'm involved with the Cyprus League Against Rheumatism. I'm a member of the board, and I'm responsible for the office we have in my town, where I live in Limassol, and I also work with ... I'm an expert patient on the expert patient list of EMA, and I'm chairing two European organisations. One is ENFA, the European Network for Fibromyalgia Associations and the other is Agora, it's a platform organisation for rheumatic patients in southern European countries.

I was involved with a group that revised the guidelines for treatment for fibromyalgia for EULAR, the European League Against Rheumatism. I was involved recently with the revision of a protocol, I was approached by the EMA and helped them on that.

I got involved in 2008 when I was diagnosed with the first disease, chronic disease, fibromyalgia, and I'm a trainer for self-management of people with chronic diseases.

WHAT KIND OF TRAINING HAVE YOU HAD TO HELP YOU WITH YOUR PATIENT ADVOCACY WORK?

The first training I did was with EULAR, the European League Against Rheumatism, and as a patient research partner we were trained on how to be involved in all this patient advocacy work and in research projects and so on, and then I was trained by EUPATI. I graduated last year, 2014.

I've learned a lot of things regarding medicine and how they are produced and the research and also it's helped me to have

the confidence to work with groups ... I mean, with people that they are involved in academics for years in this sort of thing. It helped me to gain, through the knowledge and the training, it helped me to gain the confidence to be able to sit on the table and ... I was talking before about the fibromyalgia group and it was such a great experience for me, because I was there and I was given a voice to talk about the patient advocacy, and my view as a patient and the view of another patient, because there were two of us, counted and it was taken into account and it was practically used in the final guidelines that were produced. This was a very good experience because in real life I was given the chance to talk about the patient perspective and influenced the work that was done on that particular topic.

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

The biggest challenge was the time I had to devote and the commitment to this work, because it was ... I had to do a lot of reading and it sort of took time from my family, but they were patient so I got through. That was the biggest challenge I think, and the traveling. I was really away from home for a long time, but it was worth it. It was okay, we got over the challenges finally and managed to graduate.

WHAT CHANGES WOULD YOU LIKE TO SEE IN THE FUTURE OF PATIENT ADVOCACY?

As patients we need to raise awareness between the people outside the patient community, I mean, industry and the public. We need to do a lot to raise awareness, and to do this we have to be educated and informed and I'll go back to what I said before, gain confidence to do that. Because otherwise you cannot do it, you need to know what you're talking about and

you talk to people that are very much involved so you need to have training to sort of come to an equal level.

Through all, my process it was fine. I would do exactly the same, but I need ... You need to keep reading and learning. There are so many things out there you need to be educated about.

All this training we've done, all this knowledge we've gained, we need to give it out there, it's not for us, so you need commitment and you need time and ultimately you need vision. You must feel that you need to change things, that you have a vision of a better world and do it. It's a very nice journey, it's so inspiring, so I would advise anybody that has time to do it and join the rest of us. As a team we can do a lot to change the world in terms of patient advocacy, awareness and contribute. We want to be on all levels of decision making. To do that we need to be committed and we need to be educated.