

Interview with Joan Jordan

Transcription

Hello. My name is Joan Jordan. I'm from Ireland. I've been ... Well, I've become a patient advocate since I got diagnosed with relapsing-remitting multiple sclerosis in 2010, around the same time that my son got diagnosed with a very rare form of epilepsy. After a while, I dipped my toe into the water of patient advocacy. How I started, first of all, there was an application in the Irish multiple sclerosis magazine, MS News, about would anybody like to write a blog, be involved in a group community blog. That's how I started really to get aware of issues for people with multiple sclerosis in Ireland, across Europe, and then it just kind of grew legs after that.

The blogs that I've written, I would have kind of raised issues that I would feel passionate about, maybe about access to medication or you know, issues that are important. Also, I wrote a blog about the reporting of side effects. That kind of developed in that ... I just asked why patients don't tend to report their own side effects, to own their own side effects so much, and then I got in contact with the regulator in Ireland, the NCPE. Then I attended a conference with them on pharmacovigilance. Then we started to collaborate, work together. Things have just happened since I got involved.

HOW DID YOU BECOME INVOLVED IN RESEARCH AND DEVELOPMENT, R&D, OF MEDICAL DRUGS?

It's funny that you said 'R&D' because my background is that I'm a computer scientist. I studied computer science. I worked in telecommunications for a long time, and the way that things work in that industry is that the customer is always asked constantly what do they want, what do they need. There are

quality gates the whole way through. At each quality gate, there's checks to see is this what you need, is this what you want. I find then when I became a patient there was a big transition, I thought, I felt like I wasn't really being asked what I need. Irish patients with MS weren't being asked what they need and what's most important to them and being asked about their quality of life. I felt kind of that I just took the drugs that I was given rather than of being asked about my preferences.

I did initially engage in a clinical trial for two and a half years. I actually walked the walk. I had ... every month I went to the hospital, engaged in a clinical trial, and so I feel like I've actually participated in a clinical trial. I thought that there were issues there with things like communication, and I think that improvements could be made. After that then I've gotten involved in a study. I'm one of the stakeholders. I'm a patient representative, a PPI, there. I can give my feedback then. It's about the top ten questions that should be asked about clinical trials, so it's just good to use the life experiences that I have had, not through choice, but because I have an illness like multiple sclerosis to try and make things better for patients.

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

Well, apart from the EUPATI training, in Ireland there's the National Council for Pharmacoeconomics. I got the opportunity to attend their training, again as a patient, but it was with health care professionals and members and people from the pharmaceutical industry. Opportunities have come along where I can avail of this kind of training at a national level, and then of course the EUPATI training has been very useful. Every single module has really ... It's meant that I can speak the language now. I always had the ideas in my head, I always had the motivation, but now I can communicate and speak with all

the different stakeholders so EUPATI has been ... really it's opened doors.

WHAT IMPACT HAS YOUR INVOLVEMENT AS A PATIENT EXPERT HAD?

I suppose the biggest impact really, because I am a patient myself, is that when I do write a blog about something like side effects and how important it is to report your side effects, about why certain medications aren't available. You know, I think that makes the biggest impact to me because then I hear back from patients, I get feedback. It starts a conversation and maybe enables them or empowers them to speak to their doctor. That would be, I think, where I feel I make the most impact.

Well, something really exciting has happened to me in that I have become involved in an HTA. I never expected that something like that would happen, and it's for a drug for primary progressive multiple sclerosis which there's actually no treatment available for at the moment. That's ... you know, it's something very exciting. I feel I have the vocabulary, I have the confidence. People have said to me that since I have started on the EUPATI course that I'm able to communicate, understand a lot better. Being involved in that project, in the HTA, is very exciting. This time last year I didn't even know what an HTA was.

My previous career in computer science, I just didn't have that passion, so it's something good.