Interview with Nancy Hamilton

Transcription

My name is Nancy Hamilton. Right now, I am the training manager at EURORDIS, which is the European Organisation for Rare Diseases.

I organise what we call the EURORDIS Summer School. So we train 40 patients every year at the Summer school. So I'm involved in the recruitment of patients for this training program, which has become a blended learning program of both online and face-to-face training. So I'm involved in developing the application process, selecting the patients, developing the program with a course committee and bringing those students to Barcelona once a year for the EURORDIS Summer School. And through EUPATI, I've also been involved in developing the training programs for the students in this EUPATI project. And organising the program, I'm a member of the course committee for EUPATI.

So my background is really in medical sociology. In the past, before working at EURORDIS, I worked with medical organisations, developing their continuous professional development programs. And so it's only since I've started at EURORDIS in 2012 that I've been really involved directly with patients. In the past when I was working in medical associations, it was much more with doctors, and then indirectly with the patients. But now, I have a chance to really talk to them directly and see how things are for them.

WHAT IS SO SPECIAL ABOUT THE EUPATI TRAINING PROGRAMME?

It's really amazing. I've never seen anything like this

before. So it's a one-year blended learning program, divided into six different training modules. So the students were selected from, I think, over 300 applications, we selected 50 or so students who are patients themselves often or patient advocates with a great deal of experience. And so they started this blended learning program last October and they will finish up at the beginning of November of this year. So … very intense program, that as I said, goes to the six different modules of training. So they can understand the whole process of medicine's development right up until pharmacovigilance issues, health technology assessment issues, and what role they can take in improving this system.

And what's really nice to see is the students that we trained last year, some of them have come back and are actually working as trainers this year. So they're training the second group. That's one example. Another example is, as I said, we have trained them on how they can get directly involved in all these different processes, including the regulatory process. And some of them are so well versed now in these different systems that when they are at, for example, the European Medicines Agency, often the other people in the room think that these patients are actually regulators themselves. They can't tell the difference between who the patients are and who the regulators are in the room. This gives you an idea of how well they've been trained. So it's nice to see. It's nice when someone comes back to me and said, "Oh yeah, so and so was there. But everybody thought he was a regulator. They didn't realise he was one of the EUPATI trainees." That gives you a nice sense of accomplishment.

Another big success is how they've really learned to work together. So some of them who may have felt quite isolated in the past, the group of people that they have gone through with their cohort of trainees. They've stayed in touch with each other. And they'll work together and they'll try and solve problems together. So that's been another really, really

positive outcome of the training.

WHAT ARE SOME OF THE CHALLENGES AND BARRIERS THAT PATIENT EXPERTS ARE FACED WITH IN THEIR WORK?

One of the main challenges that they are facing is moving things forward. And so one of the ways they can solve this is by working together. So when you have different trainees from different backgrounds, with different experience, sharing those experiences together and trying to do problem solving together instead of alone that solves a lot of the problem.

They not only bring their experience as patients, but they also bring their professional experience into play. So they've got all these different career backgrounds, for example, in communication, in finance and so they can understand all these different structures when they work together. So I think that's been… as I said, that's been a key aspect is they no longer feel isolated in trying to solve a lot of these issues, but they can actually work together. And that makes a big difference to them.

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

Something that has also come up over the course of the training is that patient advocates and patient experts know what to do in a lot of different situations. For example, reporting a negative side effect. But the average patient, the average person who becomes ill or is on their own to deal with a lot of these things, won't have the confidence or the skills to know how to move things forward. So I think finding ways to reach more patients is really gonna be a key for the future. Because once the students have these skills and… have the skills and the knowledge to change things and the confidence to change things, it makes a huge difference but not… I think

the percentage of patients that actually have those skills and knowledge and competencies now is still quite small. So there’s a lot of work to be done in the future to make this… the knowledge that these patient advocates have, to make it more general knowledge. And to give people the confidence to go forward and say, “This is not normal. This needs to change. We need to find new ways of doing things. You didn’t take my opinion into consideration when you made that decision.” All these things are changes that need to be made for the future.