

Interview with Klaartje Spijkers

Transcription

My name is Klaartje Spijkers. I'm from the Netherlands. I'm a mother of a young boy with the Duchenne muscular dystrophy which is a progressive muscular disorder. And I am involved as a senior project manager with the Patient Federation in the Netherlands, which is the umbrella of representing 160 patients organisations in the Netherlands, and representing the patient at the tables where decisions are made concerning healthcare, including research to medicines and new treatments.

We got the diagnosis of our son almost four years ago in December, which is a life changer. And before I was involved in the HIV/AIDS movement in education, prevention for young people and was also always very impressed by the activism of the AIDS activists because they have a power to really fight for the things they need in life. And then I realised I now am doing, I have the opportunity to do something for myself or my child. And I immediately knew that Duchenne is a rare disease and is not in the comparison of the AIDS movement which concerns millions of people in the world so the movement is big, but we can really learn from such a powerful movement in terms of connecting, which is possible with internet, bringing voices together, so I started to really look where are those voices in the world.

HOW HAS THE EUPATI TRAINING HELPED YOU

WITH YOUR ADVOCACY WORK?

EUPATI gave me the tools to be really involved and enable me to have that conversation with the different stakeholders that are involved in research and development for medicines. It gave me the network, it gave me the language, it gave me the... the toolbox, it gave me the documents. So it gave me a whole new assets how to do advocacy.

In my daily work I run a patient panel... for, as a reference in reviewing medical research proposals in the Netherlands. So researchers they have to show how they involve their patients not as a subject but as active, thinking, so active stakeholder in the whole research development. And that this panel reviews the quality or the relevance on patients involvement. And I use the knowledge obtained in the EUPATI training to capacitate the members of that panel to really be critical and provide relevant advice for the researchers to further develop their proposals. So it's, I'm trying to sort of pick out where I can use it in my daily job for instance, because I believe that being a senior project manager in patients umbrella organisation also allows me to be an advocate.

WHAT WOULD YOU LIKE TO DO DIFFERENTLY IN YOUR FUTURE PATIENT ADVOCACY WORK?

We talk about a disease, a paediatric disease. So the caregivers, the family, the parents are the first spokespersons of a young person, that we try to involve our sons as soon as possible to be their own advocates. So that we don't keep talking on their behalf, but that we, at some point, soon, try to make them their own advocates because we are seeing that, because of the standards of care, the average age is climbing. So 15 years ago, average age of death was 18, and now it's well into their 30s. So we have the task to raise independent people. So we have to also give them the skills, their own

advocacy skills as young as possible.

EUPATI is not something that is only of interest for the European level, but also for the national level. So I think the trainees and the fellows have an interesting challenge to bring the EUPATI way of thinking, the work, the experience and the knowledge to the national level and to really make sure that it's also implemented at a national level. That would be, I think, a really nice sustainability model. It's not only being involved in the European level projects, but really bring, make that connection. So I think the fellows are uniquely placed in that sense.