Interview with Jan Geissler

Transcription

My name is Jan Geissler. I'm a patient advocate now for fifteen years. I've been diagnosed with chronic myeloid leukemia in 2001. At that time, diagnosis really looked grim in the outlook. I joined the phase I and II clinical trial at that time, getting two investigational drugs, so research was actually part of my very first patient journey at that time. That is also the reason why I was so interested in research. And I became a patient advocate by trying to understand what was going on in research and trying to translate that into patient language that other patients in Germany that couldn't understand what was published in English also had the chance to understand different treatment options which they have.

Over the years, I've been deeply involved in research protocol, review of clinical trials, informed consent documents, communication about research, and so on. From being an individual with cancer, I developed into being an advocate for patients to give them access to information about research, and that has basically followed me over the past 15 years since I was diagnosed with cancer. In that, I also was involved in developing the roadmap on patient involvement in R&D because we know that patient organisations, especially in HIV, have been involved for twenty years in research, while in cancer this is much more a newer thing, but it was not on a systematic level because there was no system how industry and academic researchers and regulators, and so on, could involve patients, and that's why we designed the roadmap, really, to understand all the different steps across the whole medicines development chain where patients can be involved and how they can be involved.

I actually have two roles. My main role, my professional role, is being director of the European Patients Academy, which is a five-year project. It’s been one of the most exciting things I’ve been doing in my time as a patient advocate because what I had to learn very hard as a patient advocate … learning by doing. We’re teaching patients and patient advocates how to get involved in R&D in a very systematic level. At the same time, I’m still engaged as a patient advocate. I’m one of the co-founders and leaders of a worldwide network of one hundred and nine patient organisations in eighty-two countries in leukemia because I still do the work on the ground. I’m involved in research design and in working with researchers to do better research for patients. I actually have two roles, as a volunteer and as a professional.

HOW HAS THE EUPATI PROJECT EVOLVED OVER TIME?

When we started in 2012, the project was pioneering in a public/private partnership model. All actors in research and development were actually starting to collaborate. At that time, it was really a lot about us and them, so industry thought what patient organisations are like, patient organisations though what industry’s like, academia was thinking what patients should learn about R&D. It was, very much, everybody was still in their silos. I think, over time, we have not only developed this project to be very successful in educating about one hundred patient experts and now about forty thousand people who have used our online toolbox in seven languages, but it has also broken down the silos. Today we’re working together as a team. Everybody has interests. Everybody has a different background, and I think that’s the great thing about it.

And I think, even when this project ends, this kind of partnership and understanding for the interests and the strengths and the weaknesses of each stakeholder will

continue. I think it has made a major change to how R&D is conducted. When we started, in 2012, patient involvement in R&D was done somewhere, but there was no public debate about it. Today everybody's discussing about it at medical conferences, in industry forums, in academic research groups, in regulators, in policy on the European, on the national level. Today this is, let's say, discussed everywhere, and I think EUPATI, the European Patients' Academy, has had a major part in getting that debate and that collaboration started.

WHAT DOES THE FUTURE OF EUPATI LOOK LIKE?

We had five years of public funding and private funding to run this project as a publicly funded consortium. From the beginning, we had one work package focused on sustainability because it was clear this project will be a game changer. It will be something that builds the academy, that builds the course, that builds the toolbox, but the exploitation, the use, will come when everything has been developed. So we've been working very hard, and we can now really say proudly that this programme will continue in 2017. So it will be run as a patient-led programme, in EPF, with a spirit of a public/private partnership, with all the partners involved, and it will continue to run the course because, at the moment, we've trained ninety-eight patient advocates over two years, but there are more than five thousand rare diseases. There are more than two hundred cancers.

There are so many different, other chronic conditions. We need a patient advocate, in the end, in every kind of disease, so the course needs to continue. The toolbox needs to be provided. We need to continuously update it because the regulation is changing, with the clinical trials regulation coming into effect very soon, so we need to continue our mission. We've made the groundwork now, so EUPATI will continue as a very strong initiative, maybe even institution, from next year, when this first funding phase ends. For me,

it’s just the first phase of a continuous effort to strengthen patients in R&D.

WHAT IS SO SPECIAL ABOUT EUPATI?

It is the first time I, as a patient advocate, experienced that diabetes people work with oncology people, work with rare disease people, that we get this cross link between the experience in HIV, the pioneering spirit of the rare disease groups, let’s say, the experience of the oncology groups because it’s one of the largest problems in society with cancer. All these advocates working together, on a professional level, sharing best practice, that’s one of the most amazing thing, which I haven’t seen in advocacy, as well, because we also tend to work in silos in our own diseases, in our own medical communities. I think EUPATI has really changed that to get everyone working together across diseases, also on the advocacy. That’s amazing.