Interview with François Houÿez

Transcription

I’m François. I’m 51. I work for the European organisation for rare disease EURORDIS, where my main role is to help patients navigating through the different procedures for the development, research, evaluation of medicines, measure their needs, and we mentor them to learn how to negotiate and talk with all interested parties.

For example, when patients don’t know how to discuss a clinical trial with a company, they’ve heard that a company is starting to develop a medicine for their own disease, we organise meetings between the company and the patients. We first explain the patients all what they can discuss and how to discuss and then we accompany patients, we organise meetings with companies or sometimes public sponsors. So that’s one way and then we accompany and we continue, we mentor them throughout the development.

Another way, also very important, it’s again the mentoring idea when the CHNP, the committee that authorises medicines needs to consult with patients. This CHMP has decided to consult patients directly, particularly when they think they may take a negative opinion. And for these patients, they need to be explained what the procedures will be about, and they need to be accompanied and that’s also my role, to brief them, to accompany them so that they can provide the best contribution they can.

Something that can really help patients the most, something which is probably one of the most horrible situations patients

can be confronted to, is when they know a medicine is being developed, will soon arrive, is not there yet, and if they not have access to it now, by the time it will be available they will be dead. And society has a response to these patients that is “compassionate use”. How to obtain compassionate use, you don’t learn it at school, you learn it from all the patients who have been through that and who will help you to negotiate access to such a medicine. That is an extremely important activity.

Sometimes we help individual patients, we receive an e-mail or a call from a patient we’ve never met before, we will probably never meet anyway. They explain their situation, their problem, we help and it’s very rewarding because sometimes it’s only years later that you receive an e-mail, “Oh by the way, it worked and I’m still here, thanks.” And sometimes it’s groups of patients that we teach and how when we explain how they can obtain what they want. And I can think of some patients who were struggling in their fight to the proper information, or to the proper product at moment they needed it who survive thanks to the advice that we gave them. So for example, I remember a doctor from Belgium who contacted us because a patient was denied coverage for a medicine he needed to save his kidneys and the doctor was desperate because she didn’t know how to react. We gave her all the information she needed so that she could make an appeal, and just two weeks after interrupting his treatment, the patient was on treatment again and could save his kidney. That’s one case, there are so many individual cases all over the place that we’re ready to be organised to help them. And that is why capacity building and training such as EUPATI is really key.

WHAT ARE SOME OF THE CHALLENGES AND BARRIERS THAT PATIENT EXPERTS ARE FACED

WITH IN THEIR WORK?

Often they don’t know what they can achieve, they don’t know what they can do, they don’t know the process well enough to intervene, to play a role. Even when they know, too often they think “well…” or they’re intimidated or they think it’s too complex, impossible, so they don’t try. And others, who on the contrary will take the challenge and go to success, we know there are people that, even patients or parents, that even create their own pharmaceutical company. I can think of a mother of a child with a rare disease, she decided that the fastest way was to create her own pharmaceutical company, and they are running now a gene therapy trial, very promising product. And now they are developing the continued development of the medicine. So of course, these are exceptional cases. There are other ways to obtain a great resonance as well, which are more simple than to create your own pharmaceutical company, but which really can make a difference for yourself and your peers.

And, so other barriers … Not be intimidated, it is not finding the right people, or not finding the right interlocutor whom to talk to, or not finding the person who can train or explain you how it works and what you can do. This is why networking with organised and structured organisations, not only networking on the internet exchanging ideas with information with people, but joining the movements, the advocacy movements and the organisations where people roll east to help and guide other patients and advocates is really key.

HOW IS PATIENT INVOLVEMENT AND PATIENT ADVOCACY EVOLVING OVER TIME?

The context is changing permanently, and we’ve seen for example, the European Medicines Agency, learning on how to work with patients such an extent on last year, on more than 700 occasions, patients participated in one of the EMA

activities, and now the EMA has taken it on board and organised it smoothly for many activities so that we can focus on other activities where patients are not yet involved. So ourselves, we go from one activity or one role to the next and again discuss what can we do here, how can we push patients to be present where they are not yet present and part of the decision making process. So our role is constantly evolving because there are permanently new areas where we can learn how to play a role and bring new patients. But natural evolutionised think is also should be aware of the absolute necessity to train new generations of patients. So I think my own evolution is more now to train and empower other patients to continue the conquest rather than really acting myself. There is a risk that those who were pioneers in really advocating and providing the role patients have now, when they leave, then the next generation, they are not enough of patient advocates, won't be there, so we absolutely need to try and bring other patients on the front line.

WHAT IS ON YOUR WISH LIST FOR THE FUTURE OF PATIENT ADVOCACY?

Maybe an official recognition of the role of patients. And by official, I don't think of medals, but those who have for example decided that their entire professional life is to represent patients and to act as patient advocates. Some kind, and they've acquired such a knowledge. Not only a knowledge like at university or here in training such as EUPATI, but how to do things. A kind of recognition of the role they play could be important for others, to motivate others and to really signal to society that there is this bunch of people here, they are doing a huge job and important job, and we recognise the importance of that job. And it could be for example those who become expert in their regulatory field, why not university degree that recognises that work or they've learnt has a value and now needs to be passed to others, that's the purpose of university training and that could maybe

help.

Too often our institutions don’t realise what it means to involve civil society and patients in all their activities, in all what they planned for patients to contribute for. And of course most of patients contribute completely spontaneously on a voluntary basis, but if it is not organised, it doesn’t really contribute to what is requested from them. And to organise this, you need resources, you need training programmes, you need mentors, you need structures, you need communication methods, etc. So for institutions to engage with civil society, first means a reflection is needed on which resources to be dedicated to that, how to be organised so that it is sustainable, and so that more patients can take their role. So the message really to all European institutions national ones, is to accompany these movement by a reflection on what is needed so that it is done in the best way, with impartiality and not too much influence from other parties that really the voice of the patient can be heard everywhere needed.