

Interview with Tamás Bereczky

Transcription

My name is Tamás Bereczky, I come from Budapest, Hungary. I have been working with EUPATI as a patient representative or the representative of a patient organisation, the European AIDS Treatment Group.

Patient involvement is not only about learning the science of clinical trials, but it's also about acquiring the right tools to use this knowledge in a proper way which is policy, which is political involvement.

I've been working as a patient advocate and a peer educator in HIV for many years.

This was a hard fought struggle which took us here to the level where people living with HIV have large, strong organisations and very powerful representations in most parts of the world, in science, in politics, amongst decision makers, decision making bodies. But this is not so in other disease areas. I think that this is a true responsibility. This is something where we have to live up to this responsibility and to this task.

The bottom line is that I firmly believe that by educating people about their diseases, and making them more aware of their health, they will also become more conscious citizens and can contribute to building stronger democracies. This is the ultimate, if you like, philosophical goal of this.

When I first came here to meet these people and to talk to

them, two or even three years ago, then it was just this very shy, very timid group of patients who really didn't know what to do and how to start. They were overwhelmed by the amount of knowledge that is being conveyed by EUPATI. It's a huge amount of information that they have to absorb and they have to learn. Now when I'm back here, it's just amazing to see that it has become a network. There is a movement which is emerging out of this. There's a European patient movement which is a real grass root thing and I love it.

It's so good to see that these people are more empowered and then they just know that they have rights. They know that they can back up their rights with knowledge and thereby they can make a true impact.

WHAT ARE SOME OF THE CHALLENGES THAT PATIENT EXPERTS CAN BE FACED WITH?

There's a lot of controversy and a lot of debate about how and whether at all, you can work with other stakeholders. What is the extent to which you can accept funds from various stakeholders, including the state, the pharmaceutical industry, other funders. It's a highly politicised process. I think that just because there has been so much time going on and so much pressure in the HIV community, especially initially when people were dying literally every day, that we could come to workable models which are not necessarily perfect but they are workable.

Such as community advisory boards and other forms that have been existing in the HIV community, which I find can establish

this compromise between being pro-patient, so representing the patient's view, but also working with other stakeholders and focusing on the actual needs of the patient. Rather than getting engaged in political debates and in ideological debates, whether you can remain an activist if you accept money from the state or if you accept money from industry, rather than going into those ideological debates, we just focus on what the patients need. If HIV patients don't get treatment then they die. It's that simple.

Another important point, which is very close to my heart and this is also what many of my publications are about, is the role of emotions. That you are not less knowledgeable just because you have feelings. You certainly have feelings if you are sentenced to death at the age of twenty two or thirty five, just as it was the case with HIV. Of course you are angry, of course you are angry, frustrated and unhappy when you see your child dying and not having access to medication. Either because of financial reasons or because there is no medication, because there's no research into that given condition that your child suffers from. It does make you angry but your anger, your feelings, your frustration, your passion does not devalue your knowledge.

I think that you need passion in order to be able to acquire that knowledge. We should not be ashamed of our passion, because that's the core of activism. I think that this is, again, a lesson that we could teach pretty well to other disease areas. That, yes, you are entitled to smash the table if you are upset. But know, I mean, you should know your thing. You should learn what has to be learned in order to be able to make a passionate argument, so that passion and knowledge do not exclude each other which is the current tradition in science, you know: you're either passionate or

you're calm and a scientist, but you can't be both at the same time. I think that's the bottom line.