Interview with Dimitrios Athanasiou

Transcription

My name is Dimitrios Athanasiou. I am a parent of a child with Duchenne muscular dystrophy. I am a full-time patient advocate for Duchenne and rare diseases, in general. I got my son diagnosed before four years ago with this rare disease, Duchenne muscular dystrophy. One, three, point, erh … three and a half thousand children, and it affects mainly boys. So, after we got the diagnose, it was obvious, coming from Greece, that the knowledge was in a good level but the advocacy was not in a good level. And so, my first task was to organise the parents with the similar condition, with children with similar condition in Greece, and this is where I started from.

As I move forward, it was pretty obvious that I had to get myself trained. I had to know better the disease. I have to know better the regulators. I have to know better the process of drug development. So I tried to get some education to help me with my work. I was lucky enough to participate in one of the EURORDIS summer schools. So I have my basic knowledge acquired there. I was even more luckier to get involved in the EUPATI, which was a longer period. It was 18 months, and it was, let’s say, step-by-step from a naive patient advocate to a patient expert, was really useful for my work.

After the training, I had a very good idea which are the stakeholders. What is the balance and the interests, and how they work together, or they don’t work together, to achieve common goals. And how, as a patient advocate, your job is to facilitate that everybody works together to have new drugs in the market for all the diseases.

It gave me perspective of where do I stand in the whole spectrum of the drug development process. After that, then it offers you the chance to identifying which gaps and which areas you can get specialised and how you can affect the process. How fast the drugs and to affect it to do better. And picking up pieces from the EUPATI training and focus on that and do your homework. It gives you the tools to negotiate on a one-to-one basis with all the stakeholders, and be in a balanced position in the table, because usually the patient of advocacy, because of lack of knowledge and sometimes of perception, we are not an equal partner.

So training is very important because you are becoming an equal partner. And when everybody else is in doubt with that, when you are well-trained, and you do your homework, and you study, then you show that you can definitely be a very good partner to work with.

HOW HAVE YOU BEEN INVOLVED IN PATIENT ADVOCACY?

I have been involved originally in national advocacy. Then I was involved in our global organisation that we have from Duchenne, The United Parent Project. In my role of the Board of The Global Organisation, I had to interact with regulators. I had to interact with local and European regulators, with HTAs, with pharmaceutical, with academia, in order to produce, let’s say, better and cheaper drugs for Duchenne. So with this training, and because we are coming from rare disease, I had the chance to be a patient expert in the European Medicines Agency. And with this training, it was a very strong tool to help me do my job there better. So, I could evaluate better the clinical protocol. I could evaluate better, understand better the medicines behind it.

When I was in doubt, I was always running back to the module and to find everything I need there from my toolbox. So, it

was a backup that was so essential to do my work, at least in the scientific advice in the clinical designs of, at least my disease, that who couldn't have it any way differently. It's very difficult that I don't know what is something else that could replace it at least at this level of the European level.

When I started being a patient advocate, I knew nothing of clinical trials. Through training and through a lot of hard work and exchange with other patients, I was able to understand better the clinical trials and the models that are used in general and how those models can be adapted to Duchenne muscular dystrophy.

After I was strong enough to understand the clinical trials and after a lot of studying, I'm still participating in the steering committee of a new drug that we tried to get on the market. And to make this clinical trial meaningful for our patients… It's very important because you have a lot of clinical trials failed by design so the feedback and the patient inclusion from the start it's critical in order to have drugs available for everybody.

The informed consent process is a very complicated process and we have to make sure that the people that are participating in the trial, especially when it comes to children, they understand fully what they're getting in. In our community in general, the patient advocacy is very strong on that, so we make sure that we consult the informed consent forms, and we try to have it in lay language and to have all the information that the people want. But also for us, as full time, let's say, patient advocates, it's very important to have somewhere to look in and for other organisations, so for other fellow EUPATI to ask for more experience because we can not do solo, we cooperate together and with their experience you can also get experience to the benefit of your own community.

I started three and half years as a parent with a child with a terminal rare disease, and in three and half years I managed

to organise let’s say the advocacy groups in Greece. I’m now part of the board of directors of our global organisation. Scientific advisor, expert, patient expert for European Medical Agency, and many other roles and hats from time to time you have to contribute your experience or your time to move things forward.

I would like to add that the only barrier is the barrier we put in our mind and that we should keep pushing till we get the results we need for our patients.