

Interview with Tetiana Zamorska

Transcription

My name is Tetiana Zamorska, I'm coming from Ukraine. I live in the capitol of Ukraine, Kiev. My son was born with a rare skin disorder called, Epidermolysis Bullosa. It's a world wide known disease by the concept of Butterfly Children. Which means that kids which are born with this disease get very, extremely fragile skin. And thanks to my son he changed my life completely. Thanks to him, I became the patient advocate.

So when he was born, our family was trying to continue living the same life as we use to be, as we use to live before his birth. Meaning that my husband and I were both involved in career development. But, when our son grew to the teenager age, and he's now about 14, his disease got much worse. And that meant, for me personally, that I had to basically quit my career and fully focus my time and efforts on the disease, of my son and of other patients of Ukraine.

I was one of the founders of the first non governmental organisation in Ukraine, helping such patients as my son. We created this organisation together with two dedicated doctors, dermatologist, one from Ukraine and one from Sweden. This was five years ago. I'm very proud to say that before us, Debra Ukraine Organisation, there was nothing in Ukraine. No knowledge, no information, no registry. People suffering from this disease everywhere, throughout Ukraine, didn't know that there are other patients who also live, who also suffer, who also don't know what to do with their disease and how to treat it. I was trying for five years to combine my career with the NGO activity, but the last year made this compromise further

impossible. And I had to take the decision and fully focus on the NGO activity.

For the moment, after five years of work, there are things that I'm personally proud of, thanks to our efforts in Ukraine. We already have the registry. About 200 patients we have found in Ukraine. All these patients, they know the disease, they know what kind of medication and dressing changes they need, the bandages, thanks to efforts of our organisation, they know where to buy them. And plus, we do a lot of charity activity: We raise funds and supply free medicines to our families several times a year. These are quite expensive boxes full of medicines.

Besides that, two years ago there was a new law adopted in Ukraine on orphan diseases, and because I am a patient advocate, I understood that the most important thing for this particular moment in Ukraine's time is to really lobby legislation towards support of Butterfly Children from the government. And that was a major change in my mind, that I should not fully concentrate on fundraising and projects, using money of sponsors. Because it will always be insufficient because the disease is very costly. The cost per person, per patient, per month could range from 1,000 US dollar equivalent to 5 or \$6,000 or more. Families in Ukraine cannot afford caring about their child and bare such expenses.

That is why it was very important to me to start lobbying activities and becoming a real patient advocate, who stands in front of the patients, has a dialogue with the government: That would be the Ministry of Health of Ukraine, that would be the Ministry of Finance, who decides on the allocation of budget money. And 2016 was the first year when the money was actually allocated for Epidermolysis Bullosa patients. So, I'm helping now in this process to achieve the result. The first result would be that, this year our patients should receive first medicines on account of state money.

I'm originally a lawyer and I have two legal degrees. The applied the knowledge that I gained in my sort of prior career because all legal financial business type of knowledge and experience that I have, I utilise fully for the sake of patient advocacy, because whenever I need to calculate the costs of medicines, I need to apply financial knowledge. Whenever I structure some supply of medicines I need to conclude contracts with pharma companies and I need to apply with grant applications to donors that need to contract with them. So here, where my legal background is very well utilised.

It's about changing the legislation, it's about changing the approach to patients, it's about involving patients in all areas where they should be involved in decision making on what kind of medicines they should receive, what kind of side effects they should be informed about. It's about information and knowledge about new developments in the area of research and development outside of Ukraine that they could live and have as a hope for a future cure.