Interview with Safarali Naimov, Executive Director of Stop TB Partnership, Tajikistan

Safarali Naimov is the Executive Director of Stop TB Partnership, Tajikistan, and a member of the board of TB Europe Coalition, TBP, the global Network of People Affected by TB, and the Global Coalition of TB Activists (GCTA). Safarali is a MDR-TB survivor and has first-hand knowledge of the challenges involved with finding and adhering to treatment. Safarali co-founded the national multi-stakeholder coalition called “Stop TB Partnership, Tajikistan”, which unites and advocates for people affected by TB, and includes civil society organizations, private sector companies, celebrities, journalists and opinion leaders, to combat TB and ensure proper care and support to families and communities affected by TB. The partnership works as a civil society partner organization to the Global TB Caucus in collaboration with National TB Caucus to fighting TB in Tajikistan.

You are a member of the European Tuberculosis Research Initiative (ERI-TB) Core Group, representing civil society. The Core Group is responsible for advising the ERI-TB Secretariat on the European TB research agenda, building capacity at country level and promoting intercountry research. What was your motivation to join the network and the Core Group in particular?

For 10 years I watched as my family struggled to cope with the destructiveness of tuberculosis. I lost two of my brothers to multi-drug-resistant tuberculosis, or MDR-TB. One of my brothers died suddenly and the other passed very slowly from the disease. I also became infected with MDR-TB, and it took me four years to recover. During that time, I wondered why so little attention was being paid to TB by the medical community, by society and by policy-makers. My family and I felt forgotten and alone, and it seemed as if nothing was able to stop TB from taking its terrible toll on us.

It seemed as if there was a wall that separated the people, like us, who were struggling with TB, from the formal health-care system. So little attention was being paid to the high economic and psychological toll on the people and families who are suffering with this disease. In order to fix that, I joined the ERI-TB Core Group to understand the research area and to learn how various initiatives will help to remove the burden of the disease from the people who I represent in the Core Group. I have also worked to represent the interest of affected communities, and to be a reminder to the experts that any decision they make will have a lasting effect on the people who are suffering with this terrible disease.

Being a former patient and now a member of the Stop TB Partnership, why do you find TB research important?

Tuberculosis research is critically important to all of our current efforts to find tolerable medicines and better diagnostic tools.
Research is also a very important way for us to understand the psychological and social effects of the disease on communities and individuals.

Just like anyone else in my family’s position, I sometimes wonder what we could have done differently to have saved my brothers’ life. Perhaps if we had lived in a community that understood the seriousness of tuberculosis, maybe we would have had more support from government and health authorities. I still believe that my brothers might have survived if authorities had worked harder to coordinate the actions of our health and social systems. It has always been case that TB, at least in the former Soviet Union, is handled by the medical community and focuses more on medical institutions and hospitals and less on patients and their families.

Within communities where TB is present, the most frequent complaint is the negative side effects of TB medication. Imagine if someone at home, perhaps a sibling, has TB and you have become the primary care-giver for that person. You watch as your sibling takes the prescribed medicine and then, very soon after, vomits and rejects the medicine. Now imagine that some months later, you also have become ill with TB. Now it’s your turn to take the difficult medicine, and you also vomit, very soon after taking the prescribed dosage. This happened to me, I was actually both of those people and the side effects were horrible. I think all of us, but especially the medical authorities, need to be more aware of the physical and the emotional ups and downs experienced by most people when they are trying to cope with this illness.

We need to understand that people refuse to take medicine not because they are lazy or because they are dumb, but rather because it’s painful for them. Their body is rejecting the medicine and forcing them to vomit. This frustrates and emotionally depresses them. They know they need to take the medicine, but they can’t hold it down. So, when treating TB, health providers need to understand that people might require extra support and counselling.

The physical and mental side effects of TB treatment can be excruciating. My brothers and I could not escape the severe headaches, the vomiting, and the sensitivity to light, the body aches, the depression, or the feelings of hopelessness. In addition, the drug cycloserine, which was prescribed to cure my brother’s disease, also caused terrible psychological side effects for him. It turned him into a different person. This added an additional layer of stress on me. He ended up having to stop taking cycloserine before the psychiatrist prescribed two more drugs. Then his condition slowly improved. He felt terrible for being the cause of my stress, but I reminded him that he was my brother, and that I knew he would do the same for me.

But today it’s good to see new developments in the treatment of TB. It’s good to see that authorities are finally acknowledging the need for a rights-based approaches to treatment, which emphasize accountability and which strive to empower vulnerable and socially marginalized people. It’s also good to see the integration of the psycho-social and economic support of people with TB. We see this as a small victory!

The strain of TB bacteria you were infected with was resistant to the first-line TB treatment regimen. You decided to participate in operational research by being treated with a new regimen, which was successful. Tell us more about how this proposal to participate came to you, and were you aware of the benefits and risks it could potentially have for your health?

Finding treatment for MDR-TB took a very long time for my family and me. After several years of treatment with very few good results, we learned about the MDR-TB treatment, but saw that it was not offered in Tajikistan, and I understood that my brother would need to travel to India for treatment. I accompanied him to India, and that was how I also contracted TB. By the time we returned to Tajikistan, thankfully MDR-TB treatment was available, though only for people living in the capital, Dushanbe, and in surrounding areas. Luckily, I lived in Dushanbe and was offered treatment.

How did you find the operational research? What kind of engagement from your side was needed and how did it influence your everyday life?

It felt as if my body and mind had become a battlefield for pills and germs. I knew, of course, that this was a battle that I was going to have to endure in order to be cured. But the symptoms, which included vomiting, severe headaches, and worst of all, feelings of depression and confusion – were terrible and difficult to endure.

When I was undergoing treatment, I also desperately wanted to meet people who had experienced TB to learn more about the disease and more about how they felt after finishing treatment. I needed someone with experience to tell me that eventually I will be cured. I needed to know that everything will, after a time, be fine. This kind of awareness is worth more than gold for a person with TB.
Living with TB is frightening and one can sometimes feel as if death is inevitable. I felt that my illness was too much for my body and mind to deal with. In our culture we feel like that men must earn money for the family, while women are quite busy taking care of the home and the children. So, when a man is not able to work he feels like he is a terrible burden on his family.

When my brother was ill he could not afford to leave his job and recuperate. He was working and taking medication simultaneously. In the end, I had to resign from my job to be with my brother during his treatment in India. Later when I became ill with the disease I simply didn't have the strength to hold down a job. My wife had to quit school and she became the one who held the family together, by taking up small tailoring assignments from home.

One of my biggest worries had to do with how badly my parents would take the news of my illness. My brothers were ill with TB, and I did not want them to worry about me too. So, I hid my illness from my parents. During the first two years of my treatment, I was completely lost to my parents. I did not meet them at all. I would make up excuses like I am travelling or would pretend that I was busy. Because I had always given my parents a bit of money when I was working, my sister covered me when I was ill. She gave my parents money but made it seem as if it was me who was giving it to them.

Several years have passed since your TB was treated and your participation in the operational research. What would you like to suggest that other patients consider before agreeing to offers to participate in similar research projects?

I was one of the first people to enroll in the MDR-TB treatment for TB in my country, so I took it as my responsibility to tell people about my successful experience with the treatment programme. I tell the people I meet that trust and a positive attitude will help them to endure the treatment and its challenges.

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