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An online legal discussion board might not appear to be the most obvious place to talk about tuberculosis (TB), but this little pocket of the Internet created an outlet. It was also the place where a journalist on a national newspaper read my postings and eventually wrote a story about me. My threads prompted a lot of questions and I was eager to provide the answers, I discussed my treatment in lengthy detail on a weekly basis and the other posters would share in my ups and downs. The positive feedback I received kept my spirits up, and at the same time, I was raising awareness of an illness many people here in the UK, thought had been eradicated many decades ago.

As my treatment progressed, through research, my knowledge of the social and economic aspects of TB greatly increased – particularly the links between stigma and HIV. I defy anyone not to feel a sense of injustice at the scale of the challenge faced by the global community from a disease, which is curable.

During my first appointment at the chest clinic, my specialist gave me a snippet of information that stuck in my mind.

*“TB is one of the biggest killers of women worldwide, we’re lucky we have good doctors and access to effective treatment in this country.”*

The above quote demonstrates how complex TB is worldwide. Specific factors relating to diagnosis and treatment will often vary according to different parts of the world. I discovered in the UK, one of the main barriers faced by people affected by TB are low levels of awareness amongst the general public and the medical profession, leading to delayed diagnosis. With this in mind, I knew I wanted to do something to prevent others from experiencing the same pitfalls as I did.

Through volunteering with the UK’s National Tuberculosis Charity, TB Alert, I have taken part in various activities to raise awareness of TB and raise funds for projects here in the UK and abroad - In 2007, three and a half months after surgery to remove my left lung, I ran the 5K Hydroactive

Race in Hyde Park and raised J1,200 for TB Alert. Since 2006, I have worked with the media to raise awareness of TB, reaching millions of people all over the world. A couple of years ago, I was contacted by a man based in India who saw a BBC World documentary I took part in. He had also been diagnosed with TB and had completed treatment, but apart from his parents, I was the only “outsider” who knew about his illness. I felt very privileged that he was able to share his experience with me.

It became clear that there were a growing number of TB advocates in the UK who wanted to increase their role. In 2008, we formed the TB Action Group (TBAG), the only UK based network of people affected by TB. Recently, I was reminded of an inspirational quote by Margaret Mead, *“Never doubt that a small group of thoughtful, committed individuals can change the world. Indeed, it is the only thing that ever has”*. TBAG are a great example of this. We are a group of people affected by TB who have a unique insight in to TB services. We work together to raise awareness of TB, lobby for improved services and provide peer support to people currently going through the treatment process. My own role within the group involves handling the communications and coordinating TBAG events, particularly around World TB Day. I also contribute to local and national consultations to review TB policy and improve service design and delivery. I feel very strongly about raising TB on the UK political agenda, and involving the voice of the affected community in the response to TB on an international level.

My motivation for becoming a TB advocate is simple; I want to do something positive with my experience and to make life better for people affected by TB. I am passionate about using my experience, skills and motivation to influence other people in the fight against TB. When I was diagnosed I just wanted to be cured and to forget about TB forever, but I could not ignore the barriers facing people here in the UK and I was moved by the stories I heard from people affected by TB all over the world. We must never forget the human face behind the statistics. I often tell people that TB took away my self esteem, but it also gave me something I did not have before - a voice.

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