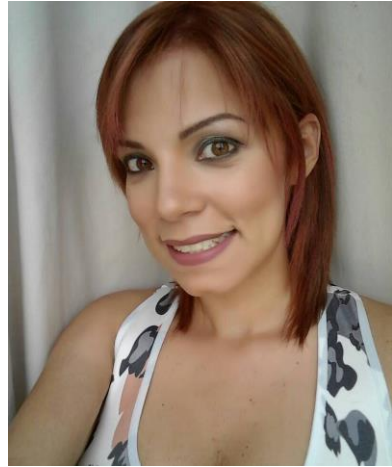


#Week8

GCTA Community Chitter Chatter on TB Stigma

This week we chat with Mileni Romero from Venezuela, a 31-year-old dentist who had extra-pulmonary TB. Living in a country that does not do drug sensitivity tests for TB and little access to medicines, she lived through TB treatment in extreme uncertainty as to what the future holds.

She went through adverse side effects of the first-line of TB drugs – from allergies to facial dermatitis and stomach problems. The severity of the side effects forced Mileni to stop treatment for several days before restarting again, but today she has come out stronger than ever.



GCTA: When you were diagnosed with TB, what were your biggest challenges?

Mileni: The biggest challenge was that I had to stop working – I am a single mother of an 11-year-old girl. My mother died when I was just a child, my father is a pensioner and my brother earns minimum wage. I was financially independent, working as a dentist. When I had to stop working there was no money to pay for basic expenses at home. With the situation in Venezuela, nobody can afford to not work.

But the most difficult part was being separated from my daughter, because the doctors told me that I could not be near her for at least the first 3 months of treatment. She has always lived with me since she was born and it was difficult to get away from her for three consecutive months for the first time in 11 years.

Also, at the beginning I felt rejected and kept myself away from everyone, including my family and friends because I did not want to infect anyone. That was hard to do.

GCTA: It is interesting that even though you had extra-pulmonary TB, your doctor advised you to stay away from your daughter. This seems to have led to self rejection as you say. Can you elaborate on this self stigma you experienced?

Mileni: I put myself in a situation where I did not allow anyone to approach me. Little by little I started shutting myself out from the outside world.

After many weeks, I reconsidered what I was doing and decided to turn the situation around and with the help of my partner I went around trying to make people understand that I am a human being who deserves respect. I started respecting myself and gave myself the courage I needed to overcome the situation I was in.

GCTA: Did you also face social stigma? Are there particular instances where you felt it was more prevalent?

Mileni: Yes, as soon as people find out what you have, they look at you like you are some kind of disease waiting to be transmitted. People look at you suspiciously and start rejecting you.

In my case, I am a doctor and patients believe that doctors are immune to everything. On hearing that I had TB, my patients started getting scared and preferred to not visit me for any kind of dental consultations. I felt I was responsible for speaking the truth, because after I said that I had TB, nobody wanted to get treated by me

GCTA: From your experience, can you think of one action that will help end self stigma and one that will help address social stigma?

Mileni: With regard to self-stigma, I find that psychological help is very important and that makes us understand that, today, TB is not a deadly disease. You can live through it and have a normal life.

To address social stigma, we must disseminate correct information to society. People need to understand what TB is: how it is transmitted, the different treatments that exist to combat it and ways to prevent TB. By making society understand this, it will drive home the point that we are not less than anyone and we will be treated as equals.

GCTA: What made you open up and start talking about TB and your experience with the disease?

Mileni: I have always been a vocal person with an inclination to help others, and this time I realized that the world needs people who can speak freely about TB, particularly to end stigma.

I feel that my experience with TB will provide support to those people who feel that they have no way out and that they are going to die. I hope that they see themselves in me as a mirror, especially because I live in an over-crowded country where there is no food and medicines (not even the basic ones for headaches, let alone antibiotics).

But in spite of all these odds, I managed to survive TB and continue with my life in a normal way – I hope people who are suffering from TB realize that everyone can overcome Tuberculosis. I hope these people who are affected by TB realize that they can live without fear and achieve all their goals in life.

Through my example, I hope people see that they can come out in the open without being rejected and learn to give themselves respect – they deserve that as human beings.