



TESTIMONIOS DE PACIENTES PARTICIPANTES EN EL ENSAYO TB- PRACTECAL

Dilaram: paciente de pauta corta

Dilaram, de 34 años, no se lo podía creer cuando le diagnosticaron tuberculosis farmacorresistente. Pero al ser una de las primeras beneficiarias de un nuevo tratamiento más corto, pudo volver rápidamente al trabajo y con sus hijos.

Al ser enfermera quirúrgica, solía hacerme revisiones médicas cada seis meses. Durante una de ellas, el radiólogo observó cambios en mis pulmones. Me mandaron hacerme una radiografía y me detectaron tuberculosis. Fue un verdadero estrés enterarme de que tenía tuberculosis. Sabía qué tipo de enfermedad era. Y no entendía cómo y cuándo podía haberme infectado siendo yo misma una profesional sanitaria. No me lo podía creer y no dejaba de preguntarme: *¿Por qué no tenía ningún síntoma?* No paraba de llorar. Cuando enfermé, mi hija mayor tenía cuatro años y la pequeña dos. Mi marido me apoyó.

Una vez confirmado mi diagnóstico, informé a mis supervisores en el hospital. De repente, empezaron a culparme de haber engañado en la revisión médica anterior. Dijeron que había comprado la licencia médica. Aunque me hice más pruebas por iniciativa propia, hubo una discusión importante sobre mi caso en la reunión médica del equipo. No mencionaron mi nombre, pero aun así me sentí fatal.

Todo eso pertenece al pasado, y no tiene sentido recordarlo ahora... Pero fue una época difícil para mí.

Recibir un nuevo tratamiento

En la clínica, el médico me dijo que había un nuevo tratamiento que podría recibir como parte de un ensayo clínico llamado TB-PRACTECAL. Me lo explicaron todo y me dijeron que podría volver a trabajar como antes, así que tenía muchas ganas de ponerme con esta pauta de seis meses para completar mi tratamiento lo antes posible.

Aunque fui una de las primeras pacientes inscritas en el ensayo clínico TB-PRACTECAL en Nukus, creía que estos nuevos medicamentos serían útiles. Tomé las pastillas con pasión positiva y no tuve ningún efecto secundario, ni siquiera dolor de estómago.

Cuando estaba en el hospital, algunos pacientes tenían miedo de empezar su tratamiento, y yo contaba mi propia experiencia para apoyarles. Siempre les decía a los demás que estos nuevos medicamentos eran buenos y que necesitábamos tomar menos cantidad de pastillas en comparación con otros enfermos de tuberculosis. Y nunca me avergoncé de mi enfermedad.

Vuelta al trabajo

Tuve que dejar de trabajar mientras seguía el tratamiento. Una vez terminado, quería volver al trabajo. Todos los resultados de mis análisis eran buenos, pero supuse que aún podría representar un problema que me aceptaran de nuevo en mi puesto de trabajo en el hospital. Así que fui directamente a hablar con el director del hospital, que era nuevo y había llegado hacía poco de Tashkent. Le pregunté si me trasladarían a algún otro departamento donde no trabajara en contacto tan directo con los pacientes como en la Unidad de Cirugía.

Le dije que había padecido esta enfermedad, pero que los resultados de mis análisis eran buenos. Le dije que estaba dispuesta a cambiar de trabajo si era necesario, pero el director del

hospital me contestó: "¿Por qué? Los resultados de tus análisis son buenos, puedes trabajar en la misma unidad".

Tras mi recuperación, quería tener otro hijo. Quería quedarme embarazada, pero después de la enfermedad tenía miedo.

En las sesiones de apoyo psicológico en grupo había oído historias de mujeres que volvían a enfermar después de quedarse embarazadas. Pregunté a mis médicos si era seguro para mí tener otro hijo. Me dijeron que estaba bien y que podía quedarme embarazada. En 2020 tuve un hijo. Es un niño sano y tranquilo. Somos felices.

Abdirakhman: short regimen patient

24-year-old mathematics student Abdirakhman had to pause his studies when he got a diagnosis of drug-resistant tuberculosis. But thanks to a shorter tuberculosis treatment course, he'll graduate soon.

My diagnosis

When I was diagnosed with drug-resistant TB in 2018, I was 20 years old. I had just started university in Nukus (Karakalpakstan, Uzbekistan), and felt perfectly happy. When I learned that I had TB, I just couldn't believe it was true. It was devastating. I felt ashamed of the disease, I was afraid to infect other people... Perhaps, it was because I was so young then, and lacked knowledge. I'm sharing my story to support people who are facing the same challenges.

At the time of my diagnosis, I only told my parents, siblings and close friends. Now I'm 24, and I wouldn't hide the disease from anyone.

Over these years, people's attitudes to tuberculosis and to people who suffer from this disease has changed. Maybe not significantly, but, for example, in my childhood if we became aware that someone got TB, the reaction was shock and fear. Adults forbid us from approaching people with TB or visit them at home - they said we could get infected.

Nowadays, if people learn that somebody got TB the reaction is different: "What a misfortune! Hopefully, the person goes to the doctor, and gets well soon, since the TB treatment exists". I'm still wary of sharing my picture – I don't know what the future will bring, but I want to share my story.

My treatment

My treatment course was short - only six months. I chose to join the TB-PRACTECAL clinical trial and was randomly selected to receive the short treatment course of six months compared to the standard two years or more. There were difficult periods but it was still better than two years of treatment. I was able to get back to studying pretty quickly.

In the TB hospital, in the evenings we used to hang out together with other patients, and some of them were on standard two-year treatment. Some of them would say: "You know, this is a trial anyway, the medications are new and are still being tested...". They doubted that our treatment was working. But we felt that the treatment worked and made us feel better.

We kept on going, and those of us on the short treatment course would encourage each other.

At the same time, the people who were on the two-year treatment course sounded rather stressed discussing it. They admitted that our treatment was much shorter. Even looking at their faces, I understood how difficult the long journey was for them.

My future

Now I have finished my course of treatment and I am back at university, studying maths. I would like to thank the doctors who helped me to recover, as I feel absolutely fine now.

I am a 4th year student now. If I had not become sick and didn't have to take leave from my studies, I would have already graduated, and would have already started working. But I feel lucky to only have missed one academic year. I want to work in a bank, - I am really interested in this work, - and I hope this will happen very soon now.

Naurizgul: short regimen patient

Innovative drug-resistant TB treatment gave me hope

Naurizgul is a 27-year-old government worker in Nukus city, Uzbekistan. In 2020, she was diagnosed with tuberculosis (TB) and later signed up to join the TB-PRACTECAL clinical trial, where she received a six-month course of treatment.

I remember 2020 as a year of highs and lows. My highlight was having my son in June 2020. This brought me such happiness. But the year also brought cons. I had COVID in September 2020. Due to COVID, I had inflammation in my lungs and was also diagnosed with TB.

The TB doctor said I needed to be hospitalised in the TB hospital, I was very upset and cried. I had a 10-week-old baby before my eyes. I wondered what would happen to my baby.

During that time, I had support from my husband and my mother, and my motivation for life increased. I knew TB was a curable disease.

The doctor informed me that I would be given two options for the treatment. First, they spoke about the standard DR-TB treatment regimens which can take up to two years, and that most patients around the world receive this treatment regimen. The second treatment option was to join a clinical trial, which was testing four different treatment options, three of which were 6-month treatment regimens consisting of a combination of new drugs, and one was a standard treatment regimen. She informed me that under the trial, the treatment option for me would be chosen at random.

I was interested in the possibility of a six-month treatment regimen and discussed it with my husband. We went to see the doctor and asked about the clinical trial and then she informed the clinical trial doctor and the counsellor who came and told me more about the clinical trial. They explained that participation in the trial was voluntary. They explained to me about the process, the regulations, and my rights as a patient. I was also informed that I could refuse without giving any reasons.

My hope at the time was that if I was lucky and put on a six-month regimen, I would return to my baby as soon as possible and my work would not be affected. I discussed this with my husband and he supported my opinion.

I was delighted when the doctor informed me that I would receive one of the six-month treatments. I started my treatment in the inpatient department on September 25 2020 and two months later, I continued my treatment as an outpatient. When I was in the hospital, my husband came to see me and supported me every day.

During the TB treatment, I had side effects including a heightened sense of smell, and I had nausea and vomited sometimes. The team took measures to manage the side effects which helped.

The counsellor listened to my inner feelings and emotions actively. They spoke with me to improve my motivation and taught me relaxation exercises.

During my treatment period, the lack of knowledge about TB among my family was clear and it was difficult to make them understand my situation. But I know that if I had not had TB, I wouldn't have known much about it either.

On March 24, 2021, I completed my course of treatment. I was able to get back to work in September 2021. Soon, my son will be two years old. I am fulfilling the tasks of daughter-in-law and mother in my family.

I think this six-month treatment regimen is convenient to the patients. If I hadn't joined the trial, I would still be on treatment now and I think this could have caused some challenges in my family and prevented me from continuing my work.

I am grateful to the clinical trial staff. They do medical checkups every two months. They do their tasks and take actions in any condition with responsibility.

I want to say to all the people who are diagnosed with TB that they can get cured. I encourage my peers to fight against TB. This disease is curable.

Sharigul, patient standard regimen

Sharigul worked all her life as a primary school teacher in Nukus (Karakalpakstan, Uzbekistan). She was diagnosed with drug-resistant TB during a yearly medical check-up that she had for her job. It was the second time she would face tuberculosis – she had survived bone TB almost 10 years before, having gone through surgery to be cured.

When I heard my diagnosis, I thought that it would be better to die. Turns out that if the God does not want you, can't do it...

It was difficult to accept that I had tuberculosis again, I went into a pretty deep depression. I cried, and was not able to hear what other people told me, even though my counselor was repeating that everything would be okay, and my family supported me a lot. My mother-in-law went above and beyond, and my husband and children did as well.

I decided to join the TB-PRACTECAL clinical trial, but I was not selected to receive the shorter six-month treatments they were researching. I hoped that I would be on the six months treatment course, as it was so short and involved taking fewer pills. But they said it was not possible for me as I was randomized to receive the standard two-year treatment course.

Taking treatment

I have two sons. The elder one is 17, he is student, training to become a policeman, the younger is 14, he is still at school. When I was on treatment, they cooked and washed dishes. I became incapable of doing anything for some time after every pills intake. It was hard to take these medicines.

At first, all my colleagues came to visit me when I was in the hospital. Even doctors were astonished by it, they asked everyone to meet outdoors and wear masks. Although everyone supported me I shut myself off from people. I wanted to be separate from them. I did not know how I would accept it if someone told me that they had this disease. I felt sad and devastated.

In fact, I shut myself off for almost 3 years. I am gradually starting to restore my contacts within my community now.

Patients supporting each other

In the hospital, other patients helped me a lot. They taught me how to take pills, how it would be easier to take medications. We talked a lot about our families... We supported each other there. It helped to cope, and I was able to successfully finish the two-year treatment period.

I could resume my work after I finished my treatment but only if I would work with older children, not in primary school. However, due to coronavirus pandemic my doctor advised me to stay at home. After all I've been through it's difficult – both physically and psychologically – to return to normal life.