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**KYRGYZ REPUBLIC**

## SUCCESS STORY

### USAID Support to People from Vulnerable Groups to Complete Treatment Pays Back as They Turn Volunteers

**The USAID Cure Tuberculosis Project works through civil society organizations to help people with TB at risk of treatment interruption to complete treatment engaging former TB patients as volunteers**



Photo Credit: Cure Tuberculosis

*Saparbek Nurmamatov, a former TB patient who became a volunteer and active advocate openly talking about TB, talks about his work and experience.*

*"He died before my eyes. And I started to think...if I don't actively fight this disease, I may also [die]... if I don't care about myself, it may happen to me. The death of this person gave me big motivation and strength. Then I started, though [I had] no appetite, to eat. One needs to eat to gain strength. And in 15 days, I started to walk and help others at the hospital... There, I started to help people," says Saparbek, a Red Crescent volunteer.*

**March 2022**

*"My name is Sapar Nurmamatov. I have three kids and a wonderful wife. And I've been working as a volunteer with the Red Crescent for about two years now," says Saparbek, a 38-year-old former tuberculosis (TB) patient and active advocate. Due to many myths and misconceptions surrounding TB, which fuel stigma and discrimination, patients are reluctant to talk about their experience, and once cured, they want to put it behind them. Saparbek is different. He is a TB survivor turned volunteer. He openly talks about the disease and uses his personal experience to motivate people with TB to adhere to treatment.*

*"I like to help people. I don't want them to be ill like I was. I don't want them to go through what I went through. I always talk about it [TB]," explains Saparbek.*

We first met Saparbek a year ago when we were preparing an online conference on the impact of COVID-19 on TB diagnosis and treatment; his poignant story about his experience of accessing treatment during the COVID-19 lockdown became a highlight of the conference. Saparbek led a simple life working at a local open-air market to provide for his family when he was diagnosed with TB in 2020 at the height of the COVID-19 pandemic. When he suddenly fell ill, his family called an ambulance but he had to wait five days to be admitted to a hospital's intensive care unit as resources were diverted to fight the ongoing pandemic.

His family could not visit him due to restrictions on visitation and movement within the city. Alone, Saparbek spent a month and a half in the hospital. In the neighboring bed, Saparbek witnessed the death of a fellow TB patient. It was on that day he promised himself to fight the disease and recover at any cost. When asked about his days in the hospital, Saparbek remembers his craving for apples, which he could not afford at the time.

Saparbek continued his nine-month-long course of treatment at home, visiting a local medical facility daily to take drugs. He was taken under the care of a Red Crescent patronage nurse, who helped him with treatment, invited him to TB patient support groups, and gave him food vouchers for his family. The nurse, Aigerim Zakirova, would showcase Saparbek's example to other TB patients to encourage them to strictly follow their treatment regimens and take drugs daily.

The USAID Cure Tuberculosis Project engages patronage nurses of the National Red Crescent Society, a project sub-grantee, to provide medical advice and psychosocial support to TB patients who are likely to refuse or interrupt treatment. Patronage nurses work with TB patients from priority groups including migrants, people who have

*"We mostly have patients with treatment adherence problems and thus have to visit them several times to ensure they do not interrupt treatment for long," explains Symyrakan Sooronova, a patronage nurse from Alamedin rayon of Chui Oblast, about the role of volunteers. "It is important that they [volunteers] actively help, the work goes on, [patients] adhere to treatment. For us, the key indicator is that they [patients] do not interrupt [treatment]. If they are lost to follow-up just for a day, we have to look for them [to return them to treatment]. I need to be sure volunteers know the territory. I introduce them to the coordinator and ask questions and we see if this person can work [as a volunteer]. Former TB patient volunteers are patients we took under patronage or were suggested by medical workers as proactive persons."*

been incarcerated, people who are homeless, inject drugs, or misuse alcohol in Chui, Talas, Issyk-Kul, Batken, and Osh Oblasts. During the pandemic, patronage nurses acted as community-based treatment supporters, delivering drugs, and observing TB patients' treatment in their homes. TB patients credit their support as a key factor in helping them complete treatment.

At the same time, former TB patient volunteers lead in-person support groups and share their experience with patients to encourage them to continue treatment. Volunteers help the patronage nurses with the distribution of monthly food vouchers for patients in need as an incentive for their adherence to TB treatment. If a patient is immobile or has movement difficulties, volunteers deliver a monthly supply of food and non-food items to the patient's home. Volunteers also distribute brochures and conduct information sessions on TB in public places to raise public awareness about TB, eliminate myths and misconceptions about the disease, and reduce stigma and discrimination against people with TB. Each patronage nurse has two volunteers, one of whom must be a former TB patient.

*"Some TB patients are reserved and they [volunteers] explain things," says Svetlana Shermatova, a senior patronage nurse from Osh. "When we visit patients, they join us and share their experiences, they say 'I too was a patient, I had this form of TB, I took drugs regularly, and now, thank God, I am healthy.' For patients, this is also a motivation. Otherwise, TB patients are regarded as pariahs by the population. Volunteers help well."*

A year later, Saparbek volunteers all of his free time to help patronage nurses build relationships with people with TB and persuade them to start or return to treatment as soon as possible to prevent the development of drug-resistant forms of TB. Saparbek is a regular in TB patient support groups where he helps patients overcome their fears and fight self-stigmatization.

In less than two years of volunteer work, Saparbek has helped 10 TB patients, all with alcohol misuse problems and under severe psychological pressure, to adhere to and complete treatment. Last year, he attended a training on volunteer work in TB and now feels better qualified to help others. Today, Saparbek uses his skills to build close relationships with new TB patients who refuse treatment and face stigmatization from their families. Saparbek's experience made him a strong believer that TB patients should not cope with their disease alone, but need to be supported by family members, medical workers, and their communities to complete treatment and recover. He also believes that people learn best from those they can trust and easily relate to.

The Cure Tuberculosis Project works with and shares stories of patients or former patients like Saparbek, for social and behavior change among TB patients, communities, and medical workers. Person-driven stories showcase the positive impact of stigma-free behavior and attitudes toward people affected by TB on their treatment and recovery. The project uses behavioral journalism along with a multiplicative dissemination approach to share information through a variety of channels, in order to foster change in the societal perception of TB and fight stigma and discrimination against people affected by TB.

*“I’ve never concealed myself. Why conceal? There is no benefit,”* says Saparbek. *“Why I don’t hide? It’s exactly because of the secrecy. When a person is ill and hides their disease, the outcome turns bad,”* he reiterates.

Saparbek wants to open a volunteer center, with volunteers like himself and his friends to reduce the burden of TB in Kyrgyzstan. He dreams of the center being a safe haven for TB patients, where they can find support, feel good, and receive the personal interaction, attention, and attitude they need. Saparbek knows how important it is.