

Siberia: A Struggle Against TB

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TB IN PRISONS: CONTAINING A CATASTROPHE

In Russia, a 16-year-old teenager arrested for getting into a fight can end up making light switches for over a year in a juvenile "colony" (labor camp for prisoners). A woman who steals a bag of potatoes can await her sentence for months or even years, locked in the cell of a "SIZO" (pre-trial detention center), where her living space is reduced to one square meter.

With almost one million prisoners, Russia's per capita prison population is second

only to that of the USA. One out of every four adult men has been incarcerated at least once in his life. Moreover, the inhumane conditions common in Russian prisons - massive overcrowding, malnutrition, lack of hygiene, sunlight and ventilation - make them an ideal breeding ground for tuberculosis, and can turn punishment for small crimes into death penalties.

TB, a contagious, airborne disease, has long been endemic in Russian prisons, but in the early and mid 90's, the disease spun out of control and reached epidemic proportions. Given the continual release of prisoners into society, the epidemic posed a major public threat. In the region of Kemerovo, in Southwestern Siberia, the yearly incidence of TB rose to over 4,000 per 100,000 inmates - 40 times more than among the civilian population. In "Colony 33" which was once the only prison colony in the region offering TB treatment, 400 persons out of 1,500 died in 1995.



Prison Colony 33, Mariinsk. Young TB patient (photo: A. Glyadelov)

Faced with this alarming situation and a shortage of anti-TB drugs, Dr. Natalia Vezhnina, the medical head of Colony 33, appealed for urgent help from international organizations. At the time, no NGOs had yet set foot in Russian prisons. Médecins Sans Frontières responded to the call and in mid 1996, it put the first 50 patients on treatment using a strategy recommended by the World Health Organization called "DOTS" - "Directly Observed Treatment Short Course".

Working in collaboration with the Ministry of Justice and regional authorities, MSF expanded its program. To date, the program has trained close to 100 medical professionals in DOTS; cured more than 5,000 people with quality drugs; established a decentralized network of laboratories; and set up a new system of screening, diagnosing, referring, treating, and following up patients, which covers the entire penal system of Kemerovo.

The impact of MSF's intervention is now visible: according to official statistics, the incidence of TB in the penitentiary system has been cut by more than 50% over five years; MSF has clearly seen mortality decrease by seven times over the same period; and, compared to three years ago,

above" before he is a doctor¹. Whether it reveals a Soviet habit of telling his superiors what they want to hear or whether it's wishful thinking, Malakhov's statement is not true: the situation is still far from being under control.



SIZO 2, Novokusnietsk. High-energy milk given to prisoners following DOTS (photo: A. Glyadelov)

the number of cases newly put on treatment is four times lower.

Dr. Igor Malakhov, the current medical head of Colony 33, says that pessimism, once rampant among patients and medical staff, has largely vanished. "We first had to convince ourselves and regain confidence in our ability to cure, and then we could pass that on to the patients. The change in mood is notable. Today the majority of the patients are optimistic. They believe in us, in our expertise, in humanitarian assistance, and they believe they will be cured. And the credit goes to all those who didn't give up - the patients, the medical personnel and MSF".

He goes so far as to say that, in the past two years, "the situation has stabilized" and that "we have the control in our hands". But one should know that Dr. Malakhov likes to present the colony he runs in a favorable light. Furthermore, he is a lieutenant colonel, and openly states himself that he is a "military man" who "follows orders from

Obstacles to TB Control

Medical reforms alone, no matter how good, will never overcome the spread of the disease. Social assistance to exprisoners is needed; alternatives to imprisonment must be found; living conditions in prisons must be improved; and above all, the penal system must be overhauled. Amnesties are not sufficient – they are only a temporary solution to release overcrowding. Long-term measures must be taken to reduce the prison population.

President Putin was recently heard on national public television (NTV) saying that last year, according to the Chief Prosecutor's Office, court "mistakes" led to the illegal imprisonment of more than 1,300 persons in Russia. No doubt the real numbers are much higher. Though a budget of about US\$ 400 million has been allocated to reforming the penal system² between now and 2006, change is slow in coming.

And while discussions about penal reforms drag on and on, the huge flow of individuals in and out of prisons continues to pose an on-going challenge to the treatment of TB. The turnover is around 25% per year. To be effective, DOTS - which lasts 6 to 8 months and involves taking a combination of four drugs - must be complete and uninterrupted. Many prisoners are set free (either because they completed their sentence, were declared innocent after months of detention, or benefited from an amnesty) before they are cured.

^{1.} With the exception of a number of civil servants, all the personnel employed in Russia's correctional institutions are military: until recently, these institutions were run by the Ministry of Interior Affairs. In 1998, responsibility was handed over to the Ministry of Justice.

^{2.} One of the key, proposed amendments is the restoration of jury trials (they existed in tsarist Russia). This system is already running (as an "experiment") in 9 regions of Russia. Valery Abramkin, a renowned human rights activist, says the "experiment" shows that juries of 12 "common people" give out non-guilty verdicts in about 20% of all cases, versus the current system of legal experts, which acquits only 1%.

A reliable TB program in civil society, with close links to the penitentiary, could ensure continuity of treatment, but such a program does not yet exist. There is also poor collaboration between the Ministry of Justice, which manages prisons, and the Ministry of Health, which manages TB structures in the civil sector.

It gets more complicated: even within the penal system, three different ministries are sometimes involved in the follow-up of a single patient. Imagine that Sasha is locked up in a SIZO, where he develops TB. He is often taken out of the SIZO and transferred to the "IVS" (or temporary isolation unit) closest to the site where he committed his crime. He is held there while his case is under investigation. Medical professionals

are rarely present at the IVS. In case of an emergency, an ambulance brings in a staff person from the closest health structure. The SIZO reports to the Ministry of Justice, the IVS to the Ministry of Internal Affairs, and the medical staff is from the Ministry of Health. There you have it.

Getting all the concerned parties in Kemerovo to sit around a table for the best interest of Sasha and some 30,000 other prisoners has been one of MSF's main efforts. The organization has helped to create a "Coordination Committee" and to devise a region-

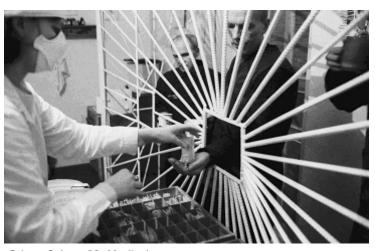
wide common strategy to control TB, which supports the regional government as the final decision-maker. Currently, MSF is pushing for the regional TB program to be approved at the federal level, and hopes such a program could serve as a model for other regions and for the nation as a whole.

Convincing authorities that DOTS is a cost-effective anti-TB strategy also remains on the agenda. "The common attitude is: 'if we only had more money, we could work well,'" says Dr. Natalia Vezhnina, who has recently taken her 20-year struggle against TB out of Colony 33 and into the civil sector with the Memorial Gorgas Institute. "But WHO standards have proven efficient in a context where resources are limited and there is an epidemic."

The public health approach of WHO gives

priority to the rapid detection, isolation, and treatment of infectious patients over those who are not infectious. Prioritizing is considered a medical imperative in an epidemic context. This approach differs from the more individualized and resource-intensive treatment methods of Russian professionals. There are other discrepancies: for example, Russians traditionally use more surgery, and they use mass fluorography (X-rays) to detect suspected TB cases, rather than the cheaper and more reliable method of collecting sputum.

When the public health structure was highly centralized and relatively robust under the Soviet Union, TB was managed impressively well. However, with the arrival of perestroika and the economic crisis, the system broke



Prison Colony 33, Mariinsk.
Patients under DOTS receive medicine (photo: A. Glyadelov)

down. And the breakdown created a manmade disaster: multi-drug resistant tuberculosis, or "MDR-TB".

This highly dangerous form of tuberculosis emerges when the TB strain has mutated and become resistant to drugs (specifically, to Rifampicine and Isionaside, the two most powerful antibiotics against "simple" TB). MDR-TB is caused by treatment that is incomplete or erratic, or by poor quality drugs. It is also contagious: a person can be directly infected with the resistant strain.

^{3.} Usually, 10% of persons carrying the TB bacillus will develop an active form of the disease. But due to decreased immunity, persons with HIV have 30 times more chances of developing TB. Drug users, the major HIV/AIDS risk group in Russia, are well represented among the prison population.

DOTS+, the treatment for MDR-TB, lasts up to two years, produces numerous side effects, is only about 60% effective, and is costly. Without treatment, about ¼ of those infected will get better, ¾ will die. It is estimated that 1 out of 10 prisoners has TB, and among those with TB, about 1 of every 5 has MDR-TB. The high prevalence of multidrug resistance among prisoners is the biggest obstacle to raising the cure rate above its current 70% mark, in order to cut the chain of transmission. Moreover, the HIV/AIDS epidemic that looms ahead could boost MDR-TB's killing rate³.

The human tragedy of MDR-TB is hidden in Colony 33, in the small town of Mariinsk. Slowly but steadily, the number of chronic patients coming from different penal institutions in Kemerovo and sent to Mariinsk has increased over the years. There are now 600 of them, most with MDR-TB, hanging on to their lives.

MSF is firmly committed and morally engaged to treat as many of these patients as it can. But it will probably have access to second line drugs at a preferential price of US\$ 3,000 per person for only 150 persons. And the start of DOTS+ is being delayed by a long series of hurdles. These range from getting final, official authorization to import these drugs to guaranteeing that DOTS+ can be continued in the civil sector whenever patients are released from the colony.

The stakes are high. "The so-called 'second-line drugs' used to treat MDR-TB are a last resort" explains Dr. Dominique Lafontaine, MSF's field coordinator in Kemerovo. "If you start DOTS+, and the DOTS+ system is poor, you can create an epidemic of 'superresistant MDR-TB'. And then you can do absolutely nothing."

"But how can a nurse even begin to explain all of this to the patients she faces every day?" asks an MSF doctor in Mariinsk, Lianne Vos. "What does she tell the young patient who asks: 'why can't I phone my parents so they can buy and bring the medicines that will cure me?' The local medical staff looked at the situation and said 'something has to be done'".

What they are doing is offering palliative care: giving the patients first-line drugs that will not cure them, but in some cases, may decrease their load of bacilli and thus ease

their suffering. The patients also do physical exercise, eat high nutrition meals, and can receive psychological counseling.

"We promote a healthy, active way of life, to motivate the patients," says the head nurse of one of the MDR-TB wards. She adds, "Because hope should be the last thing to die".

TB IN CIVIL SOCIETY: FACING A RISING EPIDEMIC

While mortality and incidence rates of tuberculosis in the penitentiary system of Kemerovo are diminishing, the epidemic is on the rise among the region's general population of three million, as it is nationwide. Last November, MSF, working jointly with many other partners, extended its anti-TB program to Kemerovo's civil society.

The Yagunovski Hospital

The foul smell is the first, shocking blow that hits occasional visitors entering the TB hospital of Yagunovski. Next is the sight of emaciated patients sinking in old, steel wire beds lining the corridors due to overcrowding. Some 200 people here have access only to two decaying showers with 11/2 hours of warm water per day. To avoid these facilities altogether, many of the patients only wash on weekends when they go home or to a friend's house. The general state of neglect of the hospital is the result of lack of funding. And when money does make it to Yagunovski, much of it disappears into cracks and leaks. Soviet, Cold War era posters still decorate the walls, instructing citizens how to protect themselves in the event of a chemical or biological weapons attack.

Discretely located among the small, wooden homes of a village just outside of Kemerovo City, the TB hospital of Yagunovksi has become a place to isolate patients who are chronically and terminally ill. A majority of them are persons of low socio-economic status: ex-prisoners, drug addicts, alcoholics, the homeless... Newly infected TB patients with a similar "profile" are also referred here. They are mainly residents of

the city of Kemerovo, but some of them also come from other towns and villages in the region (they are usually the poor who cannot pay the entry fee of 250 rubles - about US\$8 - to be admitted to the regional hospital).

In the year 2001, 150 inpatients died in Yagunovksi - almost one every other day. The medical staff expects that the mortality rate this year will be higher. In this respect, Yagunovksi is no different from hundreds of other TB health structures across Russia: the epidemic is spreading.

But signs of a new approach to containing the epidemic in the civil sector are beginning to show, even at Yagunovski. A few months ago, the medical staff introduced DOTS to the hospital, after following a training course offered by MSF. Now every day, patients line up to take their medicines under vigilant nurses' eyes.

A new effort to separate patients – the chronic, the BK positive (infectious), and the BK negative (not infectious) - is also underway. A senior nurse says "we are trying," but admits it is not easy: on the one hand, lack of space means that patients are often placed where there is an available bed; on the other hand, it is difficult to prohibit



Patients in the Yagunovski hospital

patients from wandering in a building where, for the time being, there are no physical barriers between wards. Vera, for example, is BK positive, so she has been separated from her 16 year-old-daughter Nadya, who is BK negative. Though the mother has been told and knows that "we're not supposed to see each other," emotions override medical logic, and the two regularly visit each other's wards and chat sitting next to each other on a bed.

Improving sanitary conditions is equally

challenging. The showers are in dire need of rehabilitation, but they are one of the most TB bacteria-infected areas of the hospital. An MSF engineer and logistician are wondering how they will find and hire persons willing to risk their lives to rebuild the facilities, even if these laborers accept to wear and regularly change protective masks while they work. The alternative of constructing entirely new showers is currently being studied.

Meanwhile, MSF has just finished rehabilitating the three most critical rooms of the TB laboratory located in an annex to the hospital. Local authorities decided to ferret out the needed funds that exceeded MSF's budget and are currently upgrading themselves the three remaining lab rooms. It is one of many recent illustrations of a certain momentum towards change that is picking up in the civil sector.

Patients at Yagunovski

Zhenia

At 34, Zhenia experienced his first natural high. "I felt like an angel," he says, smiling. "I felt strong, because just with the power of my brain I could overcome drugs. Sometimes I felt so strong, that it seemed to me like wings were growing on my back. I was in heaven. I don't know... I cannot explain it with words."

He calls it a "transformation". It happened at a new drug rehabilitation center in Kemerovo. A friend recommended him to go there. Now Zhenia, after being addicted to drugs on and off for 14 years, has been "clean" for eight months. Unfortunately, what he now cannot rid himself of are the drug-resistant bacteria in his body. Zhenia has MDR-TB.

His mother died of cancer when he was young, and his father was an alcoholic. He grew up in an orphanage and attended a "special school" between the ages of 8 and 16. He then worked as a construction worker for five years - until, in 1992, he developed TB.

"The surgeon told me that my right lung was OK, but I needed an operation on my left lung," says Zhenia. "He told me 'you're young, you'll get better, and you'll be fine'".

Zhenia refused to be operated on, and instead of taking medicines, he shot up with opium, to "feel good" and to forget. "I am the one to blame," he says. There is regret in his voice.

Drugs and disease pulled him into a life of isolation, homelessness, and petty theft, and soon he began drifting from institution to institution: detention centers, the TB hospital of Yagunovski, the sanatorium, and round and round again, several times a year. It is likely that he also started and stopped TB treatment many times and that this erratic pattern created his resistance to antibiotics.

Of all the places where Zhenia has lived in the past years, he was the happiest during his three-month stay at the drug rehabilitation center. There, he kept his disease "a secret". "At the center, no one knew I had TB," says Zhenia. There were no medicines there.

People just prayed - there was a 'religious regime', and many planned activities. I felt good. I was surrounded by people who weren't sick. I could talk to someone healthier than I am. My spirit needs to communicate with others".

Yet because Zhenia was worried that he might infect his "brothers and sisters", he limited his contact with them, and the amount of time he spent at the center. "I would have lunch and then leave to work, and come back to sleep. I worked at a cemetery". Why a cemetery? "It was the only job I found where I could isolate myself. And besides" - he shrugs his shoulders - "no one else wanted it".

Zhenia is silently screaming for an end to the isolation and the stigma. "I cannot pick up my nephew and hold him," he says sadly. "I've heard that in the West, they can cure TB. But here, you can only buy time..." says Zhenia. "I know that I'm chronic, that I cannot be cured, and that I will die of this disease". Still, he hopes for "a miracle" - one that will allow him "to work again, to get married, to have children". Statistically, the miracle has about a 25% chance of occurring.

Luba

Luba is seated in the sofa with her hands

neatly crossed on her lap and her slippers joined on the floor. She is wearing a long, gray gown and a white headscarf. Despite the sorrow in her eyes, she is beautiful.

She thinks she has been in Yagunovski for a week. The nurse checks the records to confirm she was admitted only 3 days ago. Perhaps it felt as long as a week. Perhaps, like the nurse says, she is showing signs of "alcoholic degradation". In any case, it is clear that Luba is disoriented and is having trouble adjusting to her new surroundings.

She comes from a village 36 kilometers from Kemerovo. She worked there in a collective farm, and her husband worked in a factory. They lived together for 13 years. "He mentally and physically abused me," she says softly. She was afraid to tell anyone, but one day she left him and went to sleep at a friend's house. Her 16 year-old-son from her previous marriage is now staying at a boarding school. She arrived at the hospital without any identification papers.

Does she know how she got TB? "I don't have the slightest idea," she says. "I heard about it before, but I didn't know it was so painful. It's hard to breathe". The disease has attacked both her lungs. She regularly stops talking to cover her mouth and let out a long, deep cough. She curls up her body and closes her eyes in an effort to overcome the pain then slowly lifts her head back up.

To the question "how do you find it here?" she responds again softly with a single word: "teplo" (warm). It is one of her many answers matching the hospital staff's suspicion that she has been homeless.

Sergei and Alexander

Sergei slept in today, so instead of his early-morning, one-kilometer jog in the forest, he got his outdoor exercise shoveling snow to clear the paths around the Yagunovski hospital grounds. This afternoon, after a game of backgammon, he will lift weights in his room.

"If I don't take care of my health, who is going to do it for me?" he says matter-of-factly. Sergei, 35, stopped working at a gas station in Kemerovo to cure his TB. After four months in Yagunovski, he is no longer contagious. He is getting better, and can feel himself regaining strength.

He laughs when asked about his nickname and reputation here as "the sportsman". Humbly, he admits that other patients sometimes try to follow his example by exercising daily. He also tries to encourage patients not to drink. "It's a stupid act. I tell them not to do it, but most of the time they don't listen to me. They realize they're doing harm to themselves." He sympathizes with the medical staff who "have a tough job" dealing with rough, intoxicated patients and trying to control the traffic of harmful substances in the hospital.

Alexander, who stays in the same hospital room as Sergei, says, "usually they start drinking when they're feeling better." He is a construction worker and ex-prisoner from a village in the north of Kemerovo with chronic tuberculosis. Though he speaks in the third person plural, until recently Alexander was himself a heavy drinker, and the strong antibiotics he is taking to cure his TB are now causing him liver problems. "They feel better," he continues, "so they think 'why not take 100 grams of vodka?' They believe they'll only do this once or twice, but then they continue".

Temptation often surfaces as soon as patients are released from the hospital. Friends and family warmly greet them when they arrive home. Traditionally, there is vodka at the dinner table, and sometimes back-to-back toasting "to your health!"

"When they drink, they lose their appetite,



Sergei, a recovering patient

they don't eat properly, they start losing weight and feeling weak, they get TB again, and months after they die" says Alexander. It's a downward spiral he's familiar with. Though he clearly links one's chances of being cured of TB with one's "way of life" and self-discipline to take medication, he seems to be only reciting a lesson. Deep down, he doesn't believe what he's learned, and he transfers his fatalism to the doctors: "They can't cure you of the disease, they can only stop it for some time".

Tatiana Elagina has been working for 20 years as a TB nurse, and for the past eight she has been in charge of the department of new cases at Yagunovski. Her feeling is that "about half the patients here want to be cured and regularly take their medicine. The other half doesn't care. People who have a family and a job want to be cured. But the homeless, the alcoholics and the drug addicts often don't understand or forget to take their pills. Social status plays an important role".

Then, of course, there are those who want to be cured but can't be. "Not everyone is lucky," she says.

Tracing Defaulters

The battle to contain the epidemic in civil society takes doctors and nurses outside of their working places and into seedy neighborhoods.

"Of course!" says Ivan loudly from his doorstep. "Aaaabsolutely! I promise to come to the clinic next week!" He flashes a smile, then joins his fingers and crosses his heart boldly, like a zealous orthodox. But it's a tune and ritual Tatiana Markina - a Russian nurse who works at a TB dispensary in the city of Kemerovo - has witnessed many times before. And still Ivan has not showed up again at the clinic. Since his wife passed away four years ago, his best excuse is that he is "too busy tending the garden alone and doing manual work around the house".

Ivan is one of many "defaulters" in Kemerovo - persons sick with tuberculosis who have interrupted their treatment. The problem is that besides putting their own lives at risk, those with active TB may infect 10 to 20 other individuals per year.

It is the job of Tatiana and more than 20 other medical professionals to comb the city on a weekly basis looking for such defaulters, and to try to lure them back to TB health structure. Unless winter temperatures below -40° C keep her indoors doing paperwork, every Wednesday Tatiana rides the bus, then sets off by foot to knock on each defaulter's door in the district of Kirovksi.

It's a neighborhood with a bad reputation. "Kirovski is dangerous," explains Tatiana. "Many ex-prisoners, alcoholics, and unemployed persons live here. So usually we go by twos — a doctor and a nurse." The rounds must start early: "Usually it's OK in the morning, but by lunchtime many of them are already drunk and aggressive".

"The tracing and home visits begin as soon as the hospital notifies us that a patient has escaped," explains the nurse. "Many patients go home because they start feeling better, and they mistakenly think they are cured. We tell them that they will infect others and that they could possibly become chronically ill and die, but these arguments rarely help".

The rare exceptions when persuasion works are what keep Tatiana going. Still, after three years of "tracing", she understandably wishes that the use of force to bring patients to TB treatment centers could be legalized - "like it was in the past," when TB control in Russia was more strict. She also regrets that laws protecting TB patients exist only on paper but are not enforced. "Sometimes patients are fired from their jobs because they have TB. It happens especially when they're employees in commercial companies".

She looks down at her list: Olga is next. She lives alone in a beaten-down house, but she often has guests, who "party and drink with her". Today, there are three young women in Olga's living room. When the nurse enters, they look down, and one of them turns to hide her face.

Tatiana knows that Olga's brother and his son both have TB, and that her brother's wife died of the disease. But she also knows that Olga's daughter was cured, and tries to use this to motivate her: "You have a positive, living example: your daughter who



Tatiana Markina, nurse

had TB but was cured" she says. Olga pulls out a plastic bag containing a mixed assortment of pills and says, "look, I'm taking my tablets". "Don't take too many of them," warns Tatiana, "you need controlled treatment". After the visit, Tatiana admits that even if Olga now "complied," it may be too late to save her life, as she has probably developed resistance to anti-TB drugs.

The indifference and denial Tatiana faces have not ceased to amaze her. Valera, for example, is a young man who, shocked when the results of a test confirmed he had active TB, ran away from the hospital and returned to his mother's home. As Tatiana has not succeeded in convincing him to come back, she has turned to his mother as a possible ally. But so far, she has found only apathy. "It's surprising how little she seems to care," says Tatiana. "I don't know why. I believe she thinks my visits are just a formality. She probably thinks I get extra money to come, and she doesn't understand the severity of her son's disease".

Neither Valera nor his mother is home today, so Tatiana heads to a poor housing project on "Initiative Street". Any "initiative" among these inhabitants was killed or numbed long ago by unemployment and alcoholism. When Tatiana first came here to visit Vladimir, a 61 year-old man who stopped his treatment and now has MDR-TB, his first question to her was: "Can I come drunk to the hospital?" "It would be funny if it weren't so sad," says Tatiana.

As usual, the door to Vladimir's apartment is open, and as usual, even though it is only noon, he is drunk. So is the 52 year-old woman he calls his "girlfriend," with whom he has lived for 15 years. The difference is

that today his girlfriend - who, according to Tatiana, is usually "in a good mood, happy and joking" - can barely sit up on the bed, and she is screaming of pain. "I never felt like I was infected with TB," she says to Tatiana, "but now I'm in so much pain, I cannot even get up!"

Vladimir argues with Tatiana, who remains calm. His speech is slurred, and only some of his sentences are intelligible: "I'll come next month, I can't come now, I have work to do! ... I'm not infectious! ... When I was in jail, the guy next to me in the cell was coughing blood, but I was fine! ... I got TB when I was fishing... it was rainy and windy, and I got a cold when I was fishing and then I got TB!"

A neighbor in his early 30's walks into the apartment and sits down on the bed. He is a regular guest. He listens to Vladimir and looks strangely at Tatiana wearing a protective mask. He doesn't know - or doesn't want to know - that his closeness to the couple, combined with the dreadful living conditions in this housing project, may turn him into the next MDR-TB victim of "Initiative Street".

Due to its high TB incidence rate, Kirovski was chosen as one of two districts where MSF will run a "demonstration site" in collaboration with local authorities and other NGOs. The site will bring DOTS treatment closer to the patients' homes. Incentives - such as the distribution of food parcels - may also be offered. The Russian Red Cross and other NGOs have found that these