

## 37 Kamskaya St., Yekaterinburg

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By Mikhail Golichenko, Senior Policy Analyst at the Canadian HIV/AIDS Legal Network

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37 Kamskaya St. is probably the most hopeless, and particularly burdensome and dense case in which Andrey Rylkov Foundation and its partners have been engaged for over 5 years. This is the place where, after five years of complaints, press conferences, roundtables, discussions, conferences, and appeals to various national and international institutions, everything has become even worse. So much worse that allocation of a room for storing dead bodies and a contract with a funeral company already appear to be good news. This is the place where stigma comes to live in some special way, in every timid rustle of patients, in the rotten smell of a field hospital and in the clear sense of death, which hangs thick in the air. In addition, 37 Kamskaya St. is an actual example of a failed state, where none of the state institutions is fulfilling its function, and regardless of what people do, the government will always do something that will only make it worse, worse, worse and worse.

The situation in the hospital is described well in two media reports, the headlines of which speak for themselves. In November 2010, *Moskovskiy Komsomolets* published an article titled "[The Last Journey Clinic](#)"; and in June 2013, the article "[Ausweis \[“pass,” in German\] to Heaven](#)". These materials are worth reading: they are written without embellishment, and every word is true.

### Initial steps and hope

Human rights activists began raising the alarm about the tuberculosis (TB) clinic at 37 Kamaskaya St., Yekaterinburg, in 2009. It was preceded by a number of complaints they received from patients at the clinic. Initial meetings were held with the phthiologists and the Chief Doctor of the Sverdlovsk Regional Center for Prevention and Control of AIDS and Infectious Diseases to clarify the “medical” part of the problem. There were attempts to meet with the local Commissioner for Human Rights and local officials. The staff of Andrey Rylkov Foundation and local organizations expected that significant positive changes would happen soon and without much effort. In the end, the issue was so serious that it deserved to be treated as a national security issue: how conditions for the spread of multi-drug-resistant tuberculosis (MDR-TB) among the public are created in a particular city in a particular medical institution, as well as for the mass mortality of patients, which would be completely avoidable under different conditions. However, it was all in vain. There have been no changes at 37 Kamskaya St.

Then, on behalf of the Andrey Rylkov Foundation (ARF), the first open [letters were sent to the Minister of Health of Sverdlovsk Region](#) and [to the Minister of Health of the Russian Federation](#), which described the terrible condition of the clinic and the quality of care.

After filing a complaint to the Ministry, NGOs [organized a press conference](#), which was attended by the Head of the Tuberculosis Service and the Head of the AIDS Center. Following the press conference, several materials were published by the print media and television. As a result, the clinic got running water, the patients were assured that testing for immune status and viral load would be conducted in the clinic facility, and that antiretroviral drugs will be provided to patients so they do not have to visit the AIDS Center to get it.

However, the main issue on access of drug-dependent people to effective drug treatment has not been resolved. At the same time, on April 16, 2010, the administration decided to make the clinic a “closed” institution; that is, the patients were not allowed to leave the building of the clinic during the

entire course of treatment (90 days on average). Since then, the patients have been held under conditions resembling those of a prison.

Patients are not allowed to have daily walks, which are important for improving the health of people with tuberculosis. The clinic administration pressures the patients, “persuading” them to write letters to the regional Ministry of Health and revoke previous complaints. People experiencing withdrawal symptoms are vulnerable and easy to manipulate.

### **Appeal to the UN**

In the absence of results of a dialogue with the local authorities and a complete absence of any reaction by the federal government, in April 2010, ARF and a number of local non-governmental organizations such as Chance Plus and Ural-Positive [submitted a complaint to the UN Special Rapporteur](#) on the right to health on behalf of several patients treated in this clinic. The complaint described the situation in the clinic in detail and noted that the issues recorded in Yekaterinburg are typical for Russia as a whole. Many patients are held in similar conditions; the only difference is they do not dare file formal complaints about their situation. Follow-ups to the complaint were sent to the UN Special Rapporteur [in 2013](#) and [2014](#). In these complaints, ARF reported that despite all the activities of civil society groups, the situation remains unchanged.

It should be noted that the UN Special Rapporteur conscientiously performed his duties. After each complaint from ARF, he tried to enter into a dialogue with the Government of the Russian Federation and, in particular, expressed his concern about the situation evolving at 37 Kamskaya St. [Here](#), for example, is his communication with the Russian government. Given the fact that the Ministry of Foreign Affairs always channels similar communications to the relevant ministries, everyone in the Ministry of Health is aware of 37 Kamaskaya St.; however, it has no effect.

### **Inspection visit**

In the summer of 2012, [journalist Alexander Delphinov visited Yekaterinburg](#). During his one-week stay in Yekaterinburg, he talked with patients of Kamskaya St. Here is an excerpt from his diary.

*Little has changed from 2010 to 2012 in the clinic at Kamskaya St.: opioid substitution therapy is still unavailable to drug-dependent patients, as well as any type of drug dependency treatment. Moreover, drug-dependent patients are discriminated against and humiliated; as a penalty, they can be expelled from the clinic without completing TB treatment. Palliative care is still absent despite the high mortality rate among patients of the clinic. As before, due consideration is not given to HIV treatment in the clinic. Patients are not informed about their condition or the course of treatment prescribed. HIV treatment has become more accessible, but some patients are offered not to take it. Some patients are requested to leave the medical institution for the reason of visiting doctors in other medical institutions. As before, there are no social workers in the clinic. With that, patients and their relatives are reluctant to write new complaints as those who signed the collective complaint to the Ministry of Health of the Sverdlovsk region last time were retaliated against by the administration of the clinic.*

### **Appeal to the prosecutor's office**

In December 2012, Sverdlovsk regional charitable organization Chance Plus [filed a complaint](#) to the prosecutor's office of Zheleznodorozhny district of Yekaterinburg on violations of the rights of drug-dependent people at the TB clinic at Kamskaya St..

From the complaint: “According to the Sverdlovsk regional AIDS Center, in the last year, 729 people died from the triple pathology of HIV infection, tuberculosis and drug dependency. This all happens because drug-dependent people do not receive any drug dependency treatment; and they are not able to stop using drugs right here and now by themselves. Due to the absence of drug dependency

*treatment, most patients are admitted to this clinic several times, and often at the last admission they have multi-resistant TB, which is not treatable, and therefore — to die”.*

The prosecutor's office “channeled” the complaint to health authorities, who conducted a formal investigation of the clinic’s work and informed: “No major violations in clinic’s activities were found”. In the eyes of health professionals, mortality, dead bodies, expelling patients with active TB who purchase drugs off-site, numerous complaints with the horrific details of the doctors’ attitude to patients – all of these are within the “norm” of operations of a health care facility in a country that is one of the Big Eight [G8].

### **Round table, square chair**

On April 2, 2013, in Yekaterinburg, the Andrey Rylkov Foundation and Sverdlovsk regional charitable organization Chance Plus held a joint [press conference](#) at the network resource center Dorogami Dobra (“ways of kindness”). Once again, the topic of discussion was the inaccessibility of a comprehensive treatment of TB, HIV and drug dependency, which leads to the fact that patients with such a complex combination of diseases are dismissed from the clinic in connection with disciplinary violations, do not get TB treatment and die. The clinic is still lacking a specialist narcologist.

On April 5, 2013, in Yekaterinburg, there was a [roundtable](#) organized by the three NGOs: Sverdlovsk regional charitable organization Chance Plus, regional public foundation New Life and Sverdlovsk regional organization Active Participation. The roundtable was devoted to providing quality treatment to TB and HIV co-infection among drug-dependent people in Yekaterinburg and in particular, to the situation at the Kamskaya clinic. The roundtable was attended by not only human rights activists, but also officials: D.R. Medvedskaya, Deputy Minister of Health; T.G. Merzlyakov, Human Rights Commissioner in the Sverdlovsk Region; A.V. Podymova, Chief Doctor of the State Health Care Institution Regional AIDS Center; heads of the TB Service public health agencies; A.N. Popov, head of primary and emergency health care; O.V. Zabrodin, chief consulting narcologist of the region.

The NGO representatives drew the officials’ attention to a number of issues, including the absence of spots available in TB clinics, which are required by people living with HIV and seriously ill with TB. Ms. Medvedskaya suggested increasing the number of spots in hospitals available for concomitant pathology of HIV and tuberculosis. The deadline for fulfillment of these obligations was set for May 15, 2013.

But despite these pledges, little changed by the summer of 2013:

- T.G. Merzlyakova never arrived to Kamskaya. Thus, all of her efforts to protect the rights of the patients at this clinic were limited to her participation at a meeting of the Federal Service for Supervision of Consumer Rights Protection and Human Welfare (Rosпотrebnadzor).
- The number of spots available for patients with concomitant pathology of HIV and tuberculosis has not been increased, neither by May 15 nor after this date, despite the Deputy Minister of Health’s pledges.
- The specialist narcologist has not started working at the clinic.
- An employee from Chance Plus is not allowed to consult patients on their drug dependency issues, despite the allegedly reached agreement.
- Representatives of Chance Plus were not even provided with the minutes of the working meeting at which all these pledges were made.

Furthermore, [more complaints have been received](#) from patients of Kamskaya on illegal dismissals, human rights violations and incorrect treatment. However, the patients’ relatives are so intimidated by the whole situation that they try to hold their tongues and not raise a fuss for fear of their loved ones being expelled from the clinic for violating the internal regulations.

### **Response of the authorities and health care workers: baiting patients and civil society organizations**

The Investigative Committee of the Russian Federation conducted an inspection into Chance Plus based on a statement of staff of 37 Kamskaya St. that claimed that Chance Plus provides “protection to drug traffickers,” “propagandizes and compulsively forces doctors to prescribe narcotic drugs such as methadone” and “slanders.”

After the July 2013 *Moskovskiy Komsomolets* article was published, the doctors of Kamskaya [filed a defamation lawsuit in court](#). The clinic's Dr. Fominykh claimed six counts of defamation in the remarks of one of the patients interviewed for the story. The defendant presented medical documents, certificates from the ambulance services, extracts from medical records and registration logs for each of the charges together with copies of complaints other patients, who fully confirmed the remarks made in the interview, sent to the public health authorities.

The judge faced a difficult dilemma: under the law, in defamation cases, one may distinguish statements of fact from value statement. If the defendant proves the truthfulness of the statements of fact, the claim should be dismissed. Value statements cannot be checked for authenticity; they stay within the framework of freedom of expression. The defendant (in this case, the patient) supported all the facts with medical documents. Moreover, the defendant proved that his value statements did not appear out of the blue but resulted from the failure of the doctors to fulfill their duty to inform patients about the course of treatment prescribed. Under the law, the claim had to be dismissed.

But the judge opted to make an interesting maneuver. On one hand, he admitted Dr. Fominykh's numerous diplomas, certificates and other qualifications documents as acceptable evidence. These documents, however, were not material for the case as they did not have any probative value: the doctors' professional credentials were not the focus of the newspaper article. But these documents had a tremendous prejudicial effect by creating grounds for a biased hearing of the case, saying that the plaintiff is a doctor with the highest qualifications, with diplomas and certificates, and who is the defendant? A drug user, who has only himself to thank for what has happened to him, and above all, because of the drug use he is guilty for violating internal hospital regulations. Moreover, the fact that he was not given fever-reducing drugs, despite having a fever is explained by the “doctor knows best” — if the doctor said to endure, one must endure. Even more, he is guilty for violating the regulations: he was advised that the regulations prohibit use of drugs, which means no drugs allowed, but the regulations say nothing about drug dependency, so no drug dependency exists.

On the other hand, the judge ordered a linguistic study of the news article. Linguist Ms. Plotnikova came to the conclusion that the article provided negative information about Ms. Fominykh in the form of “value statements which can be factually verified”. Despite the fact that the laws of the Russian Federation, the Supreme Court of the Russian Federation and the European Court of Human Rights require distinguishing statements of fact from value statements, Plotnikova (who is not required to know the laws) combined these all into one. And the judge (who is required to know the laws) admitted Ms. Plotnikova's conclusion as acceptable evidence and used it as the [basis for his judgment](#).

Thus, a biased hearing of the case occurred when the judge relinquished his main function of evidence evaluation to Ms. Plotnikova. In other words, a kangaroo court.

The ARF and its partners' work didn't end there. A complaint was filed to the European Court of Human Rights, as the violation of freedom of expression in this case is obvious.

With that, the case materials allow one to trace how profound stigma has permeated the authorities' every step, including the court's decision.

### **Behind-the-scenes of doctors' bureaucracy, or let's hit drug dependency with a panic button**

The case resulting from Dr. Fominykh's claim allowed a look inside the bureaucratic processes that took place in 2009 in connection with the petitions of ARF and its partners to government agencies and ministries.

It turns out that investigations on 37 Kamskaya St., in fact, have been conducted. There was a committee of health officials verifying the facts from the *Moskovskiy Komsomolets* article. According to the committee meeting minutes, the committee noticed both the fever of 37.8°C and the dismissals for “violating the regulations,” but no major violations were found because the treatment “is conducted in accordance with the Order of ...” by “qualified professionals” and “in accordance with the internal regulations.” The committee failed to see that the “violators” of the regulations are people suffering from drug dependency, who “violate” the regulations because such means of treatment as a “regulation” or “an order” does not exist among the effective means of drug dependency treatment anywhere in the world.

The Committee protocol is a waste product of a bureaucracy, when the result of work by an institution in the form of an extremely high and entirely preventable mortality rate is considered the norm because everything is “conducted in accordance with the Order,” by qualified staff and in accordance with the internal regulations.

The committee concluded that “the information in the article ‘*Ausweis* to heaven’... is a reflection of the views of individuals who systematically violated the regulations of the clinic.” Decisions based on the investigation findings were made to address both parties to the conflict: doctors and patients. The protocol states that “a conference on the topic Ethics and Deontology in Medicine should be conducted for medical staff.” And that “it is necessary to restore the ‘panic button’ and access control in the clinic” for patients. Stigma was clearly evident in the report: “violators” of the regulations do not deserve access to effective health care, the absence of which forces them to violate the regulations (i.e. use drugs), but they deserve a panic button and access control.

Dr. Fominykh was not idle either. No, she did not try to fight for patients’ access to drug dependency treatment. She appealed to regional and city council deputies, the community liaison office of the Communist Party of RF, as well as to the Commissioner for Human Rights in the Sverdlovsk region. All claims are identical in content and requirements – establish access control, tighten security, “involve” the law enforcement agencies. In all claims Dr. Fominykh speaks about her patients as follows: “Tuberculosis patients ... walk around the city, ride public transport, partake of the sacrament in the church from the same spoon as healthy church members, kiss the holy crosses and icons. Our patients love to go to churches ... TB patients, as a rule, are irresponsible and malevolent people. The TB toxin affecting the person’s nervous system distorts their thinking. Such patients reason and say something like this: ‘I am not the only one to get this. Let others suffer too’.”

These letters are imbued with deep stigma against patients. The doctor hates her patients and instead of trying to improve treatment and ensure access to effective drug dependency treatment, she is trying to turn the clinic into a prison.

From the materials in the case, it is clear that none of the bureaucratic structures have even attempted to solve the problems of 37 Kamskaya St. by medical means. Even the Regional Commissioner for Human Rights, in her correspondence with the Chief Doctor of 37 Kamskaya St., advised the Chief Doctor to “consider an option of regulating the rules of patients’ personal stuff search” and that the Commissioner for Human Rights is ready to involve law enforcement agencies in the problems of the clinic.

In other words, stigma against patients with drug dependency, HIV and tuberculosis is such that all bureaucratic structures are ready to tighten access control, involve law enforcement agencies, restrict patients or force them to do something. However, they are absolutely not ready even to begin considering a question on more effective work practices accepted worldwide for patients with comorbidities of drug dependency, TB and HIV infection. Nevertheless, other civilized countries have abandoned tuberculosis clinics and have been practicing treatment according to [DOTS System](#) for a long time. But not in Russia. To justify the selected treatment methods, Dr. Fominykh in court referred to a handbook published in 1985 (two authors of which had already died by the time it was published, which suggests that the book was written much earlier).

## **Heads up! A question**

Why do the bureaucrats, institutions and doctors hate their patients? Why do they exist at all, if they cannot properly respond to continuously incoming signals about the obvious distress in a particular institution? How did the value of a human life become lower than internal regulations made up by whoever for a single medical institution? How could such a system of health care management be established, where the stigma against patients is the basis for decision-making?

## **Epilogue**

We have been in the 21st century for over 14 years. Somewhere in the world scientists are testing the latest prosthetic devices (artificial arms, legs, eyes, increasing life duration) and doctors are in court defending the rights of their patients. Presidents of countries are putting their careers at risk for laws that will increase the availability of health care or laws that will change failing drug control regulations. Entrepreneurs give billions' worth of business projects to governments as gifts with the sole purpose to begin mass production of environmentally friendly transportation vehicles. The movement for rights, the eradication of stigma and discrimination is in line with the times. Progress is where this happens.

Places where life is ruled by the stigma will always be a failed state, where doctors hate their patients, officials place miserable orders above human life, and patients ... "love to attend churches, kiss the crosses and icons..."

*P.S. We have not posted the materials and documents related to the different stages of the case here, as they contain personal data, and it would take too much time to white them out. However, if someone has a legitimate need to become familiar with them, feel free to send an email to [rylkov.foundation@gmail.com](mailto:rylkov.foundation@gmail.com).*