



Trying to survive

Kostya Proletarsky. The last interview

Interviewer: Anya Sarang

English translation: Vitaly Djuma, Shona Schonning

On 20 November 2008, a Russian newspaper, Novie Izvestia, reported that one of the courts in Karelia [a region in Russia's North-West] made a precedent judgment in a case to release a prisoner with a advanced AIDS due to his bad health condition. The prisoner was able to prove that he needed urgent treatment

which he could only get outside prison. Many people, who read the news in the International Treatment Preparedness Coalition's Russian listserv (ITPCru), sighed with relief: the prisoner referred to in the news, was Kostya Proletarsky – a social worker in the harm reduction project of the Humanitarian Action Foundation in St. Petersburg, HIV activist, and our dear friend. On 31 October 2008, Kostya was released for health reasons from the medical correctional facility No. 4 in Segez' rayon in Karelia [150 km south of Arctic Polar Circle]. Since then, Kostya spent most of the time in the Botkin hospital in St. Petersburg, trying to treat what a few years in a the prison colony did to his health. I used to visit him in the hospital when I would come to St. Pete. His stories about his life in the colony hurt and appalled me and I kept asking him to write them down but Kostya would not write anything longer than a text message. Then I decided to interview him and record our talk about those unforgettable years in the colony and about lives of ordinary inmates co-infected with HIV and TB.

Anya Sarang [AS]: Ok, let's roll.

Kostya Proletarsky [KP]: In 2006, I was sentenced to three years in ordinary confinement. Later, in the prison, they found out that I had TB. From time to time all prisoners get X-rays and when I got mine they said I had infiltrative pulmonary TB. They transferred me to a prison hospital where I spent half a year.

AS: And you also had HIV?

KP: Yes, I had HIV. I already had HIV when I got put in prison. When they brought me to the prison, I said that I had HIV and AIDS and that I had started taking ARVs because my clinical condition called for it., I started therapy in the AIDS Center in St. Pete, within GLOBUS project... I was taking the first line: Stocrin, Combivir. When I got to prison, I explained my situation to all the doctors who saw me, I explained, that having the medicines was a matter of life and death for me, that I can't interrupt the treatment. They told me to calm down ... And they didn't give me anything. They told me they didn't have those medicines, they didn't have connections with the AIDS Center... basically, they were out of the loop and they didn't have anything.

AS: Were you offered TB treatment?

KP: Well, this is how it looked: they opened the feeding bunk and threw in all the pills – here you are, take it... And that's it! The nurse gave same pills to everyone - and each inmate had a different diagnosis. She would give us all the same pill and said, “swallow it”. In fact, she didn't care if you were swallowing them or not. They didn't check at all if people were treated or not.

AS: So, while you did your three years, you weren't receiving ART at all?

KP: Not at all. Later I was transferred to Karelia to Onda – the TB colony. A medical correctional facility. When I got there, I told all the doctors that I had advanced AIDS, told them everything, showed my last medical records... But nothing, no effect. When I came there in 2007, many inmates with HIV had been transferred there and they didn't know what to do with them. They hadn't even registered us as HIV patients - we were listed as TB patients. So they put all the inmates with HIV in one barrack and didn't let us out at all. We were fed in the sleeping barrack. We didn't move around the colony at all. And when you'd tell doctor examining you that you're HIV positive, he was like, “I have no clue, what are you talking about, what is this?” There were only TB doctors there, no infectious diseases specialists, no dermatologists.

AS: And the TB doctors didn't know anything about HIV?

KP: Of course, nothing at all. And for a long time we had been listed as TB patients, not as HIV patients. And more and more people with HIV were transferred to that colony.... The barrack couldn't hold all those with HIV... So they had to make a separate brigade, "turbo-HIV" [TB+HIV]... And now it is the largest brigade in the camp.

AS: So what was it like, this brigade

KP: In principle, it is a maximum security brigade. Well, there is nothing there: no medicines, they gave you TB drugs even if you have bad hepatitis or something else... They don't give any supporting therapy. Not for liver, not for anything... There were many deaths there, I saw too many of them, many people were dying. And it was spoiling the indicators for the camp, so the administration started to transfer the people that were close to death, with HIV, to Medvezhegorsk... It is a prison hospital, central prison hospital in Karelia.

AS: And what's going on there? Were you there?

KP: I was there. I got very sick in spring of 2007 or 2008. I had a fever of 40 [degrees Celsius] for a whole week. The doctors couldn't do anything, they couldn't understand what was going on. They knew though that all inmates with HIV are sent to Medvezhegorsk. It is a big colony. There is a therapy barrack there. A surgery barrack. A TB barrack. So they sent me there. I sat there for two weeks in SHIZO, and that was it...

AS: SHIZO? What is it?

KP: SHIZO* - it's a punishment isolation chamber.

* [Russian – SHtrafnoy IZOlyator]

AS: Why did you end up there?

KP: Because at that time all people with HIV had to be isolated. Even in the prison hospital, they put us in the isolation chamber in the basement, get it? Can you imagine?! A punishment isolation chamber. The chamber I was put in was very small, about 2 meters long. Two bunks chained to the wall, something like a WC – a rock - in the corner and a sink, and that's it. There were two of us there.

...And so the doctor [in Medvezhegorsk] calls me and says: well, what's up with you, why did they bring you here, why was it necessary... So I told him, explained everything... He said: wow, I've learned something from you! That was after I told him about viral load, ARV and stuff, he didn't know anything about it... he said, "wow, you're so well-versed, you must be from St. Pete..." And that's it, during the two weeks that I was there he saw me only once and I was transferred back.

AS: So, didn't they treat you at all at that hospital?

KP: They didn't do anything. For two or three weeks I sat in the isolation chamber and then was just sent back.

AS: Did they do any tests? For HIV? Immune status?

KP: No, they don't do anything there. He took my blood, said it was for viral load. I believed him. After that he put me in the transfer list to send me back to my colony. I told him, "Why are you doing this, let's at least wait for the results," and he said, "I will send it to your colony." That never happened.

AS: And in the colony, they kept you in a SHIZO, too?

KP: No. Well the SHIZOs are for those who were just arriving. After that, they sort everyone out. Can you imagine - in the TB colony there were two sections one for 'HIVs' and for 'healthies'... in a TB colony! The 'healthys' are those with TB.... The rest are 'HIVs'. So, this guy walks by and nearly falling down and he's a 'healthy.' And I'm an 'HIV'.

AS: You said many people died in the colony... Do you know why?

KP: It's hard to say. I don't think all of them died of TB but all of them had HIV. I saw one guy getting a spinal tap. And the day after, he lost his sight. He had a fever. He was transferred there. They thought he had TB, they kept giving him all kind of antibiotics, strong ones, kept injecting but he wouldn't get better... Then a specialist came there, said it might be meningitis, "let's do a tap. So, right there in the colony, they do the tap. The day after, he loses his sight, and gets a fever. They transfer him to Medvezhegorsk... They arrange for a car right away, a security guard... They took him away quickly. But he died in the end. Imagine? And there are too many like him there...

Another one had flare up of hepatitis. They stuffed him with TB drugs, which are highly toxic, so awful. And his stomach kept swelling, he was all yellow. He told the doctors that he was feeling real bad and they just answered that they didn't know anything.

AS: So it's like - "we don't know what a liver is... We don't care, we treat TB here."

KP: Right. You know how it is... You come to the doctor's office, they give you pills and look in your mouth to make sure you swallow them. If you don't swallow and you take a pill with you

from there, you get 15 days in a punishment cell. So the guy kept eating the pills... In the end he got ascite, drum belly. And he died. At a dinner time. We had dinner, and he died. In our ward. Imagine this. This stuff we had... It's hard. I just received a letter from the colony. A guy wrote to me, we sat there together. He says he recently was in Medvezhegorsk... He says, "Kostya, it's a real morgue, you can't imagine it... Remember this guy, and that one, and that one..." He started listing all the names in the letter and lost count...

AS: Of those who died?

KP: Yes, yes, he listed so many names... Its really horrible. He says it's a tomb. Everybody is literally dying.

AS: Had they been transferred to Medvezhegorsk to die?

KP: Well, yea that's basically it. So that they don't die in the colony where the other inmates would see it - they were transferred.

AS: And what about families? Didn't they do anything at all about this situation?

KP: I don't know of any cases... in which there was a reaction... I think nobody really cared... There were people who got released early.. It happens when an inmate can't serve his jail time for health reasons anymore.. At that point they are pretty close to death.

AS: What health conditions should one have to get released?! If one is half-dead and on the way to Medvezhegorsk.?

KP: Well, sometimes they don't transfer them, there was one guy who was just carried out on a stretcher. He was released. So they carried him out on a stretcher and gave him to his parents, imagine? His mom freaked out, I think... Well, you see pitiful remains of your son at the prison gate... Take that. Imagine?

AS: That's harsh.

KP: The colony in general is harsh. Remember what I told you about bleach? Well, it's for everybody, not only for those with HIV... It's when after you arrive in a colony, they take the frills out of you, so to say. To show you who's boss. They pour bleach with ammonia onto the ward. Thirty litres of bleach mixed with ammonia and hot water. This all is poured on the floor... It's so thick, just horrible! When I stood there, I looked down and I could see the fumes coming up from the wooden floor. Can you, imagine!?

AS: Why do they do that? What sense does it make?

KP: Hmm, I don't know, honestly... Well, just to jeer someone. Nobody explains anything. They break you down psychologically, morally. The gas they make is so strong that you come close to fainting, get it? When it burns your eyes, you can't breathe, foam comes out of your stomach. Even your face starts... I don't know how to describe it... Its like everything is being dissolved, like being eaten, you know? And after that it hurts all over your body for a few days. When I came to the colony, I had infiltrative TB, not so serious, no holes, no focuses. Just some blackenings... And after one month in the prison, after several punishments with this bleach, they do an X-ray and say that both of my lungs started disintegrating.

AS: Several punishments?? So this happens on a regular basis?

KP: Well, yes. We arrived there: in the punishment chamber they poured bleach several times, then in quarantine...

AS: So, they do it as if its disinfection? I just can't understand how they justify doing that.

KP: It's not disinfection... Nobody justifies anything. I am telling you, it's to break you down morally.

AS: But they can't just write in their protocols that they pour bleach to break people down morally. There has to be some kind of justification.

KP: Yes, it's not justified at all. You know what they say: there is no bleach in Onda. None at all. Nobody pours anything on anyone. Officially it doesn't happen. But it does happen. It's like a gas chamber. They pour it and you just can't breathe. I remember it... It was a room half a size of my ward -very small. They packed twenty people in there - inmates. And you couldn't see further than a half a meter - the bleach was in the air already. And people started suffocating right away. Some fainted and fell down. Panicking, people started breaking the door... they were trying to save their lives-you know. And they knocked the door out together with a piece of the wall - just trying to survive.

AS: How did they explain why they were doing this?

KP: It's for punishment. For something what the colony administration doesn't like... It's still happening there, I'm sure. Always has been. That's that.

AS: Ok. So... what other fun did you guys have there, apart from the gas chamber?

KP: Fun... Apart the gas chamber, they would put me in a gas mask where the filter was replaced with a bottle with ammonia, 1.5 liter, imagine. There was a situation that I had nothing to do with. But in the colony, there were many people who could defame you for their own benefit. That's how it happened to me. A guy was being released and he asked me for an AIDS Center address and all the phone numbers where people with HIV could get any info. And it was prohibited to take such things as personal notes outside of colony. And when they searched him at the exit, they found those notes and thought it was kind of cipher writing. So I was severely punished. I was inhaling ammonia for a quite long time. And then they put a special note in my file that I might be receiving narcotics in my personal deliveries. So they would open everything in my packages without leaving anything intact. I all the fish and condensed milk and everything pours out. I have waited for this package two months, and they just explode it. So I go back to the barrack with empty hands.

AS: So they did this thing with ammonia to make you tell them something or just as "punishment"?

KP: Well, yes. They didn't ask me to tell anything. They just knew that that info came from me. They asked me about it a few times, but I said I didn't write anything. And they replied "we don't need your confession, we caught that guy so it doesn't matter what you say." ... That's it, imagine? And all I did was giving an address of the AIDS Center.

Many things happened there... There were many dead bodies, of course... Once, when there were already 150 people with HIV and we all were in one barrack, closed, isolated... Those TB

doctors didn't know what to do with us... So, these doctors from the commission of infectious diseases came... They had probably been told just yesterday that they'd be infectious diseases doctors from then on... So here's what kind of doctors they were. They gazed at us with interest. They keep coming there until now, guys from the colony just called me. So one guy told me these doctors came there last week to prescribe ARV. I was like wow, cool! And that guy has TB, he has a disability status because of TB, he already had skin diseases – his whole body is like one of lizard, condyloma, candidosis and stuff. They looked at him, at his face and said: it's too early for you so start ARV. That's how they do diagnostics... They don't need anything, they can do everything... telepathically.

AS: How long were you in that colony?

KP: A year and eight months... I served two years and three months out of four years that I had been sentenced to, and one year and eight months in that colony.

AS: So, they didn't treat HIV there at all?

KP: No, they didn't treat it at all. They didn't even list us people with HIV anywhere. Because an HIV patient in the prison means a certain diet, state subsidies, some additional money is supposed to be allocated for an inmate with HIV. And they didn't have it. We spent one year, even more, listed as TB patients, not HIV patients; there were no HIV.

Now they call and tell me that they get ARVs but when I was there in 2008, only one of 180 HIV patients was receiving ARV. He was local, from Karelia. And he was receiving it because he started [the treatment] in the AIDS Centre in Petrozavodsk [capital city of Karelia] and his treatment had had good results. So the doctors were sending him ARV to the colony on their own. I asked them if I could get ARVs. They said no, because I was from St. Petersburg. And that guy was local, from Karelia. The budget of the local AIDS Center was designed to include him.

AS: Couldn't you had it mailed from St. Pete?

KP: But how? I hadn't been taking pills for one and a half year in the prison and I couldn't go with the same regimen. I needed diagnostics, maybe I had drug resistance, maybe I needed other drugs. And nobody did anything like this with me. A lawyer came to me with somebody like a forensic examiner, a kind of doctor... So they didn't even let him in to examine me. And he was my lawyer with an official contract. They came especially for this – to collect all the documents for the court to release me for health reasons. So they didn't let him in to me and we were talking through the glass.

AS: How did they explain to you that they didn't let him in?

KP: Nobody explains anything to inmates there.

AS: How did they feed you?

KP: All the same... The food was meagre. Barley, just a bit of meat... A diet for TB patients: half litre milk in the morning, one egg in two days. Half litre milk every day, that was stable, whole milk or in powder. A porridge made with water. Fifty grams of butter and bread. For lunch we had, I don't know, you can't really call it soup... It was something, kind of liquid, with green pickled tomatoes. And barley gruel with kind of stewed meat. It was pork... But I think they

didn't slaughter swines, they died on their own – that's how the meat smelled... I'm telling you truth. But people don't eat there. It was almost impossible to eat what they give us there.

AS: Did they give you some vegetables?

KP: No. No vegetables, no fruits... I didn't eat any single fruit while I was there. There were vegetables but only cooked or canned... I only remember green pickled tomatoes, cooked in plain water – that was soup. Disgusting. Everybody waited for the evening when we had time off. In time off I could take my sack and eat what I bought in the [colony] shop or received in delivery. But only less than 40 % get deliveries. The rest don't have families, and they have to eat what they get [in prison]. The food is low-calorie, considering that they give strong drugs ... In principle you need to feed tuberculosis, you need to keep the calories coming in so that tuberculosis eats the calories, not you... You need calories. And we didn't have them there at all. It was horrible.

AS: And what about drugs?

KP: There are no drugs there. On Onda, there are no drugs, no alcohol. Onda is that medical correctional facility No. 4, a TB colony. The Onda water reservoir is close to there and it is a part of the White Sea - Belomorkanal. It's just 5 km from the colony to the White Sea - Baltic canal. So, no drugs, no alcohol, because it's a very tightly guarded colony. There are people sentenced with different confinements: minimum security, high security, particular treatment. But it doesn't matter. There are no separate brigades. Everybody is under one ferocious security.

AS: Tell me how you managed to get out of there?

KP: I was released on parole. My lawyer came to me and the [prison] administration called me afterwards, and asked me why the lawyer kept coming to me. It's quite rare in those forests. So I told them he was hired to get me out on parole. And they started telling me, "why do you need this, it's less than one year left from your sentence, maybe you would write the request on your own? We would let you out, in principle. Maybe you will change your mind." I said "ok, let's do it. I didn't want to argue with them. In a few months, I received several rewards and then went to the commission. You come to the head of the institution, and it's all big cheeses there, big stars on their shoulders, all the managers of the colony. The head asks you several questions. He asked me where I would go after the release and something about employment. I told him I would go home. He asked the others: well, shall we release him? Everybody nodded their heads. One month later the court took place. I was released on 31 October.

AS: If it is so easy to leave from there, why doesn't everybody get released?

KP: A year ago, it was a mere fantasy to be released on parole. Very rare. I don't know what people did to get released on parole. Because the [colony] administration would not let you out, and if you would send a letter "through a box" – you could send a closed letter to the judge and the censorship didn't have the right to open it – so these letters would come back to your colony anyway. So [after that] some people would get "bleach treatment", some would lose his status if they held any position [in the prison system], some would be transferred to another brigade. They would not let it happen even if an inmate would have all the right to this. And then something changed. Oh yes! A colonel from the [regional penitentiary] department came in the spring 2008 and visited all brigades... So, he comes to the HIV brigade and says, "I know that there's a bunch of you here is from St. Petersburg - you all should submit claims for a parole, we

don't need you here, you can serve time at your place... If you don't have any infractions – write petitions for a parole, we'll let you all out,” he says, “we don't know what to do with you. With your turbo-HIV. He came and lined us up, he went back and forth along the line and told us this ...

AS: After you were released, did you come back to St. Petersburg?

KP: I was released on 31 October, 2008. Before that, while still in the colony, I got really sick; one month before the release I had a high fever. I came to doctors, asked for help, told them “please see me, what’s going on with me?” And they told me, “go away, Proletarsky, you’re leaving soon anyway, don’t bother us. So the last month I’ve been awfully sick... Didn’t know what to do. I couldn’t wait for the release day since the doctors didn’t want to see me. So I came back home with a 40 degrees [Celsius] fever. I spent a few days home and came to the Botkin Hospital [for infectious diseases] on 11 November. I had exacerbation of TB. I had high fever for one a half – two months, they couldn’t send it down... Now they want to start ART to me, but they can’t... It’s active TB... They don’t want to risk. It’s a 50/50 risk: either TB will exacerbate to the lethal outcome or everything will be fine...

AS: Due to immune status?

KP: Well, yes. I’ve seen very many people here in the Botkin Hospital die after they started ART. They had tuberculosis of lymph nodes. And a few month later they would die. So I told it to the doctor, Svetlana. She kept telling me: let’s start ART. And I told her that I saw so many deaths after ART had been started and I feel frightened...

AS: What’s your CD4 count now?

KP: The last time I had 134, the one before the last one it was 104. And she told me there was a certain risk, 50-50. I tell her, it’s too big so I won’t risk so far. But they insist ... And other doctors came here, international experts, they say to treat TB first and then start ART. One should see the dynamics. Now infiltration in my right lung increased so the TB is still developing. In general, spring and autumn are exacerbation periods for TB patients...

AS: Did you get prescribed the second line [TB] drugs here in Botkina?

KP: Yes

AS: So you got your drug-resistance in the colony?

KP: They identified I was resistant to six [TB] drugs. In the colony. But they gave me what they had. Sometimes it was two drugs, sometimes - three drugs... Sometimes they didn’t give any at all because they didn’t have any.

AS: But why did they give you those drugs if they knew you had drug resistance?

KP: Well, that’s the way it is. An inmate should eat TB pills. It doesn’t matter whether they are effective or not. It happens that there are no drugs at all... Weren’t supplied or something else...

AS: Did it happen often?

KP: Well, there were interruption with antibiotics... It happened that there were drugs for one brigade, but not for other. It’s horrible there, it’s a tomb there.

AS: And what happens with people after the release? You are lucky, all of St. Pete knows you, but what about others?

KP: One guy called me just recently, he went to Medvezhegorsk in very bad condition... They sent him there. And we didn't hear from him, we thought he already died... And so he called me the other day, "hi, it's me, XYZ, I have been released for health reasons, I'm coming home to St. Pete now." And he has very bad TB and HIV... They prescribed him ARV in Medvezhegorsk, he's been on ART for two months... He was released and he comes to St. Pete and wants to go to the hospital because he is very sick. He was released for health reasons which means he is dying. So he comes to the TB hospital to get registered... And he says he wants to be put in hospital, says he was released for health reasons, shows all the medical certificates. And they tell him: look, there is only one ward for turbo-HIV in St. Petersburg. So you need to get on the waiting list, you should wait a month or two. And people are treated in TB hospitals for several months, it's hard to treat – so you can wait a long time for your turn. So he called me and asked if he can come to the Botkin Hospital. I went to Musatov [deputy head of the hospital] to put in a word for him... But he tells me that the guy has fibrous-cavernous TB and he can't put him in the hospital with this diagnosis – no special wards for this. He has 100% open TB, wards are small, so he will infect everybody. I can't help him. He should go to the AIDS Centre, maybe with their support he can get into the turboHIV department. So he came to the AIDS Centre and they told him: why did you show up here? Go back to your hospital, wait for your turn...

Anya Sarang: After I finished editing the interview transcript, I wanted to show it to Kostya to check a few things. I asked friends in St. Pete to bring the interview to Kostya to check a few details. But my friends wrote back that on that day Kostya was in coma. His health wasn't getting better since the winter; the treatment of his drug-resistant TB was not successful. Because of that he couldn't start ARV treatment as the risk was too high. For several months he had had high fever of 38-40 degrees Celsius. He was suspected of having of tuberculous meningitis and tuberculous of the spleen. On the top of all that, because of his drug addiction Kostya just couldn't stay in the hospital all the time, he had to leave it every day, with high fever, sometimes he went away for weeks. It was useless to persuade or tell him anything. That's why Konstantin Lezhentsev [from the Ukrainian Network of PLHIV] agreed with the AIDS Centre in Kiev [capital city of Ukraine] that they would take care of inpatient treatment for Kostya including TB treatment - and substitution therapy so that he would not need to run away from the hospital. We were just going to bring Kostya to Kiev when he decided to leave the Botkin Hospital, yet again, to "relax" and have drugs. And two days later an ambulance brought Kostya to the TB hospital for "turboHIV", in coma and with tuberculous meningitis. For us, the four days of Kostya's being in coma were time of despair and hope. I kept telling everybody around that if Kostya survived Onda, he would fight the coma. I hoped so much. But Kostya died on 19 June 2009 at 6 o'clock in the evening.