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HIV Patients 'Lab Rats' Amid Drug Shortage

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About 75,900 people receive anti-retrovirus therapy in Russia, and 190,000 more need it, according to the Global Fund to Fight AIDS, Tuberculosis and Malaria.

Only a lawsuit helped Irina, 28, a HIV-positive computer programmer, obtain her regular medicine — which her life depends on — from a state-run AIDS center created especially to provide treatment to HIV-positive patients.

The Moscow-based center never denied Irina treatment altogether but replaced the usual anti-retrovirus medicine with another, less preferable drug, citing delayed supplies from the Health and Social Development Ministry.

"We live in constant fear that there will be no medicine," Irina said in a telephone interview.

She spoke on condition that her real name not be used, saying she did not want to risk angering the authorities and being denied treatment. Her last name was released by court web

sites, but they did not say what her lawsuit was about.

A change of medication is a big issue for HIV-positive people because any drug has severe side effects and takes a long time to get used to, Irina's lawyer, Ilnur Sharapov, said by telephone.

Irina said her old medicine took a month to get used to. "The first two weeks I felt so nauseous I could not get out of bed," she said. But the medicine improved her condition.

Treatment centers in 44 regions had to resort to replacement drugs this year, apparently because of bureaucratic mess-ups caused by state agencies shifting responsibilities for procurement and distribution among themselves.

Supplies were delayed nationwide this year because the Health and Social Development Ministry, which buys medicine for HIV patients once a year, was two months too late initiating a tender for suppliers, Vadim Pokrovsky, head of the Federal AIDS Center, said in a telephone interview.

The ministry, which took over the responsibility for HIV drug purchases from the Federal Consumer Protection Service this year, might have been unfamiliar with the buying process, which likely caused the delay, Pokrovsky said.

A telephone request for comment submitted to the ministry on Oct. 14 had not been answered by Monday.

Lawsuits, regardless of outcome, are an effective measure to obtain regular treatment, but many patients avoid public exposure linked with going to a court because of the social stigma associated with HIV, Sharapov said.

In particular, Irina's lawsuit was rejected by the city's Izmailovsky District Court in August but still prompted doctors to provide her with the medicine she had requested.

Irina has appealed the decision in the Moscow City Court, which upheld a lower court's ruling on Oct. 26, Sharapov said.

Nine HIV-positive people in Moscow, Kazan, Tula and Arkhangelsk also managed to obtain their regular medicine after they sued AIDS centers, said Pavel Chikov, head of the Agora independent rights watchdog that provided them with legal support.

A Kazan court ruled this summer that local doctors illegally deprived 56 minors of HIV medicine for three months. The doctors eventually managed to get the required drugs but had to obtain them from other regions.

In both Arkhangelsk and Tula, local AIDS centers acknowledged in separate ongoing trials that medicine had not been provided to several patients.

In Irina's case, the court ruled that doctors had the right to replace the drug if they deemed it necessary, said Sharapov, who also works with Agora. But, he added, the decision went against HIV treatment regulations that only allow a change in medicine if the treatment had unbearable side-effects or was not effective, which was not the case.

Still, the Moscow AIDS center has not admitted to a medicine shortage in court, saying the drug change was needed to improve treatment.

"As it was, the judge ruled that HIV patients are laboratory rats that can be experimented upon," Sharapov said.

HIV-positive people have to take a cocktail of three drugs, and one of them was replaced for Irina with a medicine that has the side effect of lipodystrophia, which makes "the fat go off your cheeks while you grow a belly or a hump," Irina said.

"This not only feels scary but looks scary," she said.

The medicine's active component, stavudine, which induces lipodystrophia, was banned by the World Health Organization late last year, before it was prescribed to Irina.

Still, most HIV patients are "afraid to go to court for fear, perhaps an unreasonable one, of spoiling relations with doctors and getting no medicine at all," Sharapov said.

He said people also fear "publicly revealing their status because our society is strongly prejudiced against HIV patients and they can lose their job and friends."

Moscow AIDS center officials asked a reporter to get permission from City Hall's health care department for them to comment for this article.

A request submitted to the health care department Oct. 15 has not been answered. City Hall personnel have been undergoing a shuffle after the appointment of Mayor Sergei Sobyanin in late October.

A law obliging authorities to provide medicine to HIV-positive people free of charge was passed in 1995, but international organizations financed the programs since at least 2002.

The government took over the job in 2006, after it implemented a national health care project, but doctors started seeing HIV drug shortages right away, he said.

This year's tender was announced in June, which probably resulted in some regions running low on drugs, Pokrovsky said.

The ministry acknowledged in mid-September that some regional AIDS centers have experienced shortages, but did not elaborate.

HIV-positive people who staged two protests in Red Square in mid-September said up to 45 regions saw drug shortages this year, Agora's web site Openinform.ru reported. The first shortages date back to March, Chikov said.

He said red tape, "the lack of practice or motivation," or a "corruption component" in the purchase of the costly medicine may be to blame for the delays.

Medicine importers have to "get permission from an incredible number of officials," Chikov said.

HIV treatment costs from $1,000 to $10,000 per patient a year, Pokrovsky said.

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State statistics put the number of HIV-positive people in Russia over the last 25 years at 570,000, with 75,000 of them deceased, Pokrovsky said. But unofficial estimates say the real figures may be as high as 1.5 million.

The number of HIV-positive Russians has grown 7 to 10 percent every year because of cuts in prevention programs, Pokrovsky said.

Forty-two programs in 20 regions were terminated in August by the government, which cited budgetary concerns, the Russian Health Care Foundation reported on its web site in September.

The Global Fund to Fight AIDS, Tuberculosis and Malaria will also withdraw from financing HIV treatment and prevention programs in Russia by next fall because it only helps countries officially considered poor, Pokrovsky said.

The government has allotted 14.5 billion rubles ($474 million) to HIV prevention measures in 2010, HIVpolicy.ru reported.

Pokrovsky said the amount of money was sufficient but bureaucracy prevented it from being spent effectively.

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