

# Russia's HIV/AIDS epidemic is getting worse, not better



In 2015, a dermatologist in Russia's fourth largest city, Yekaterinburg, diagnosed Katia with herpes. "I had no idea what it was," says Katia, who asked that her last name not be used. But because she had suffered repeated illnesses over the preceding 2 years and had an alcoholic ex-boyfriend who simultaneously had other girlfriends, she suspected that something more serious might be wrong. She asked the doctor to give her a referral for an HIV test. "Why?" he asked. "Are you going to marry a foreigner?"

"I persisted and said, 'I'm not leaving here until I get a referral.'"

The day Katia learned the test results, she walked the streets for hours crying, unable to even find her car. The literature she received explained she had the AIDS virus and said the outlook was grim. She read that the virus, if untreated, could kill her in as few as 3 years. Katia, then 30, had a young daughter. Who would raise her? And Katia had to hide her infection from her employer—her father. "If I told my father I had HIV, he wouldn't understand. He'd run away from me. Overall, the attitude here is horrible. When I look at [Western] Europe or the United States, I don't understand why it's so different here."

For Katia, the differences between east and west would soon become far starker.

Since 2015, the World Health Organization (WHO) in Geneva, Switzerland, has recommended treating everyone who tests positive for HIV, but doctors—despite what the literature suggested—assured Katia her immune system hadn't suffered enough damage to warrant antiretrovirals (ARVs). Two years later, Katia was married to a new partner and wanted to have another child. She had read on social media that HIV was a scam by Big Pharma, but that made no sense to her because the government promises free treatment. Other sites said proper treatment would almost eliminate her risk of transmitting the virus to her husband, who was uninfected, or their baby. She went to the AIDS center and requested ARVs. "They told me, 'Don't worry, your level of virus is low, you won't infect your husband, he's in the military and he's strong.'" Finally, in February

2017, after more than 2 months and a battery of tests, the doctors agreed to treat her, and in May, she became pregnant.

In June, the pharmacy ran out of ARVs.

Through social media, Katia contacted an HIV-infected woman, 2000 kilometers away in St. Petersburg, who was part of a “reserve pharmacy”—a network that gathers and redistributes ARVs from people who have either switched treatments or died. The woman told Katia whom to contact in Yekaterinburg. “I asked how much the pills would cost,” Katia says. “She was like, ‘Are you out of your mind? Just go and get your pills.’”

Almost anywhere in the world, an HIV-infected woman who has an uninfected partner and wants to have a baby would be first in line to receive ARVs. The challenges Katia faced in getting treatment amid Russia’s epidemic highlight the country’s faltering response, which critics have blasted as misguided, lackadaisical, and downright dismissive. Some federal health officials even question the term epidemic. “This is a very large and very serious epidemic, and certainly one of the few epidemics in the world that continues to get worse rather than get better,” says Vinay Saldanha, the Moscow-based regional director for the Joint United Nations Programme on HIV/AIDS (UNAIDS) in Eastern Europe and Central Asia. “This is a public health crisis.”

Yet the informal network of HIV-infected people that ultimately supplied Katia with ARVs highlights another, less recognized side of Russia’s response. The darker the night, as Fyodor Dostoevsky wrote in *Crime and Punishment*, the brighter the stars. Bold, committed HIV/AIDS advocates in Russia are pushing hard for change—and a few places in the country show signs, albeit modest, of mounting effective responses.

UNAIDS calculates that between 2010 and 2015, Russia accounted for more than 80% of the new HIV infections in the entire Eastern European and the Central Asian region. By Russia’s own estimates, the epidemic grew 10% per year during that period, with the new infections roughly split between people who inject drugs and heterosexual transmission. At about the same time, new infections in the rest of Europe and North America dropped by 9%. By the end of 2017, the Russian Ministry of Health estimates, just shy of 1 million people were living with HIV. Even official accounts acknowledge that only one-third of those receive ARVs.

Many people, even within the government, think those estimates understate the epidemic. Vadim Pokrovsky, who heads the Federal Scientific and Methodological Center for Prevention and Control of AIDS in Moscow, an epidemiological surveillance arm that's independent from the Ministry of Health, does battle with the divisions that oversee HIV and tuberculosis (TB). His group estimates that between 1.1 million and 1.4 million Russians are infected with HIV. And Michel Kazatchkine, the United Nations secretary-general's special envoy for AIDS in Eastern Europe and Central Asia based in Geneva, and colleagues concluded in a study published last year that the true number of infected people may be as high as 2 million. They based their number on an estimate by Pokrovsky's team that only half the infected people in Russia knew their HIV status in 2013.

Kazatchkine, who earlier headed The Global Fund to Fight AIDS, Tuberculosis and Malaria, also in Geneva, says Russia has unnecessarily let a containable epidemic explode. "Having gone through years of AIDS in Europe and then in Africa and everywhere as head of The Global Fund, I just cannot accept that there have been so many missed opportunities," he says.

HIV took off in Russia in the mid-1990s, later than in Western European countries, and at first the spread was limited mainly to heroin users sharing needles and syringes. Even before he took over The Global Fund in 2007, Kazatchkine and others urged the government to use proven "harm reduction" prevention strategies, including needle and syringe exchange programs and opiate substitutes such as methadone. Several nongovernmental organizations (NGOs) started programs for drug users, but the government offered no funding for what it saw as "Western" ideas that went against conservative Russian culture—and to this day opiate substitutes remain outlawed. The government also did little for another highly stigmatized group, men who have sex with men (MSM), who also are at high risk of infection. Since 2013, a "propaganda law" has made posting or discussing information geared toward MSM illegal. They rely on NGOs for many HIV services, as do sex workers.

Compounding the problem, several NGOs left the country starting a decade ago after Russia, emboldened by a strengthening economy, began phasing out The Global Fund's support—which to date has totaled \$378 million. "They said, 'We don't need The Global Fund or money from outside; we'll cover everything ourselves,' but they didn't do it," Pokrovsky says. "We not only stopped outreach work, we lost many people working in NGOs because they had no federal

support.” Other NGOs pulled up stakes after President Vladimir Putin in 2013 enacted a law that forced many of them to register as “foreign agents.”

“They basically let the epidemic grow because of lack of prevention and because of very low access to treatment,” Kazatchkine says. “In short, they did it all wrong.”

No program yet provides ARVs to high-risk uninfected people, a prevention strategy called pre-exposure prophylaxis (PrEP) that has had remarkable success, particularly with MSM in Western Europe, Australia, and the United States. “Who would PrEP be for?” Kazatchkine quips. “There are no MSM.”

On top of all those challenges, Russia has a dysfunctional medical system, says Olga Bogolyubova, a psychologist who did HIV/AIDS research in St. Petersburg but, fed up, moved to the United States in 2015. Bogolyubova, who works at Clarkson University in Potsdam, New York, says Russia’s broken system vastly complicates attempts to add HIV/AIDS programs for vulnerable populations. “The Russian medical system can be difficult to navigate and abusive even to people who aren’t vulnerable,” she says, noting long waits to see specialists and short supplies of medicines for many conditions. “A navy admiral recently shot himself because he couldn’t get access to cancer care.”



Maria Jacovleva (left), who directs the nongovernmental organization Candle, does HIV testing at a St. Petersburg vegan bar, Animal.

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Tereza Kasaeva, a deputy director of the Ministry of Health who coordinates the country’s HIV/AIDS programs (after meeting with Science in November 2017, she became head of WHO’s Global TB Programme), acknowledges that Russia “didn’t pay much attention” to the problem until the past 5 years, but she says the current criticism is overblown. “Everybody is talking about the need to avoid stigma,” Kasaeva says. “We are against the stigma on the Russian Federation about the situation.”

Kasaeva and her colleagues stress that the number of people getting treatment has increased severalfold over the past few years, and they note that they recently completed their first strategic plan to battle the disease. “We understand that now we have a problem and we’re trying to solve it,” she says. Everyone who

requests treatment receives it, she insists, although some “people are trying to hide” and don’t request it. Yes, shortages of ARVs occurred in some places last year, but that was only because of speed bumps in a shift away from regional drug purchase and distribution to a more streamlined, cost-effective federally run program.

Kasaeva recognizes that harm reduction programs might slow HIV’s spread in the short term, but they don’t address underlying problems, she says. “They’re very popular and they look so smart and pretty, but in fact if we look into the problem deeply, it’s not solving the problem.” Harm reduction, “according to the opinion of a huge number of Russian experts,” focuses on the symptoms and not the causes of addiction, she says. In contrast, the country’s “systematic program of rehabilitation for drug users,” she insists, has long-term effectiveness.

Yevgeny Roizman, who until last month was the powerful mayor of Yekaterinburg, has embraced that effort. (Roizman resigned in protest after regional lawmakers voted to end direct election of the mayor.) In 1999 he started a rehab program called City Without Drugs that, at the request of parents, forcibly removed teen addicts from their homes and locked them up while they went through withdrawal, chaining them to their beds at times. Criticism from human rights groups—featured prominently in Western European and U.S. media—and lawsuits ultimately shut the centers, but Roizman offers no apologies. He insists the program helped his region, the Sverdlovsk Oblast, eliminate heroin addiction and slow the spread of HIV. “My goal was to stop youth from using drugs,” Roizman says. Although he offers few hard numbers to back his claims that the program worked, he has an abundance of anecdotes, proudly noting that he recently located 22 of the first teens treated at City Without Drugs who now have 38 kids of their own. “They’re not doing drugs ever since they got to us,” he says.



Yevgeny Roizman, former mayor of Yekaterinburg, Russia, has opened a museum of religious icons. He has taken a hardline stance against drug users.

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Roizman sees no need for harm reduction programs for drug users; NGOs that offered needle exchange in Yekaterinburg failed to make a dent, he says. He visited Ukraine, which legalized opiate substitution therapy, to see how it worked. “An army of heroin addicts,” he says, was “reconfigured into an army of

methadone addicts.”

In other ways, however, Roizman’s agenda is not entirely at odds with the international HIV/AIDS community, and he has a progressive bent. A published poet who opened a free museum of religious icon painting and sculpture, he strongly supported the opposition to Putin in the March election and is critical of “the main government officials” for not speaking about HIV. Roizman promotes condoms and sex education for teens. And he publicly took an HIV test himself to encourage people to know their status and start treatment if needed. “There are more serious problems and issues that we have to battle, but bearing in mind the dynamics, we do understand that HIV might just steal the future.”

A different approach is in view on the banks of the Volga River in Kazan, the capital of the Republic of Tatarstan. Kazan’s ornate kremlin (which means “fortress”), replete with both a mosque and a cathedral, dates back to Ivan the Terrible in the 16th century. The city has fanciful buildings of more recent vintage, too: a 30-meter-tall, copper-colored cauldron, a wedding palace built in 2013; and a swank soccer arena that opened the same year and is hosting World Cup games this month. The city is well-heeled, with an unusually large Muslim population for this part of Russia and a long history of independence—which helps explain why it stands out in its HIV/AIDS response.

Kazan in 1999 began aggressive needle and syringe exchange programs and other harm reduction efforts with support from NGOs, the semiautonomous republic itself, and eventually The Global Fund. “We’ve had a stable epidemic,” says Larisa Badrieva, an epidemiologist and researcher there. “We really reached a lot of people very, very quickly.” The city recorded about 1000 new HIV cases in 2001, she says, and that number fell to about 150 in 2008, with little evidence that the virus was spreading to the general population. A relatively high percentage of HIV-infected people in Tatarstan—about 50%—is being treated with ARVs. Yet Badrieva is worried about the future. With the pullout of The Global Fund and with other outside assistance drying up, Badrieva says only one of seven centers in the city dedicated to drug users is still operating, and she is unsure whether it will remain open much longer. “Unless there’s a dramatic shift in the drug scene, we’ll see an increase of HIV infection across all groups,” Badrieva predicts.



Vyacheslav Ignatenko (right), holding a tray of opiate cooking equipment,

receives bags of syringes from a needle exchange in Kazan, Russia.

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Like Kazan, St. Petersburg is often out of step with Moscow and has made solid headway against HIV/AIDS. The most westernized city in the country, St. Petersburg “is kind of an oasis,” says Gregory Vergus, who works with an HIV/AIDS NGO called the International Treatment Preparedness Coalition. As a federal city, St. Petersburg directly receives funding from Moscow for HIV prevention, and Vergus says it invests the money wisely, focusing on vulnerable groups. “Most regions spend their HIV prevention money on balloons, songs, and working with grannies,” he says.

Saldanha says he’s particularly heartened about the latest data from the city. “We’re hoping that St. Petersburg has now turned the corner,” he says. In 2016, new infections in the city dropped below 2000 people a year for the first time since the epidemic took off, according to the city’s AIDS center. Of the 36,000 residents who know they are living with HIV, about half now receive ARVs, and 82% of that group have undetectable levels of virus in their blood, meaning they are adhering to their treatment regimens. “We’re doing something right,” says Tatiana Vinogradova, deputy director of the St. Petersburg AIDS Center.

St. Petersburg still faces serious challenges, Vinogradova notes. Recent surveys that tested large groups of sex workers and MSM both showed double-digit prevalence of HIV, and only about 5% of the people already knew their status. Many migrants who have HIV also come to the region from former Soviet countries and do not have the proper St. Petersburg registration necessary to receive treatment and care. “It’s a big problem, and we have no instruments to do anything about it,” she says.

Still, Saldanha says, the fact that “St. Petersburg is finally pulling its head above water” gives him hope for the country as a whole. “It’s very much a sign that in contemporary Russia, you can implement evidence-based HIV prevention programs,” he says. But St. Petersburg is only one city in a highly populated, geographically expansive country. “They have a treatment coverage level that is half what it is in Zimbabwe,” he stresses. “This epidemic is not going to go away on its own.”

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## Jon Cohen

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