

# A Battle Against Death or Fear?

## Fighting the HIV Virus Rather Than its Victims

BY VIRA ILLIASH

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The morning of May 16th was bright and sunny, with a cool breeze that kept the clouds from covering the sun and carried emotional voices and snatches of speeches across the square: Love ... Remember ... Live. "What are they talking about?" asked a passerby, addressing the small group of people gathered around the Red Ribbon Monument at Kiev-Pechersk Laura, an Orthodox monastery in Kiev. Someone replied, "Today is a day of remembrance for people who have died of HIV/AIDS." With an anxious glance, the passerby nervously hurried away.

The handfull of people, mainly journalists and representatives of HIV service organizations, went on listening to the short speeches made by doctors, politicians, and leaders of philanthropic and non-governmental organizations (NGOs) who have taken up the struggle against this disease and its insidious, but consistent, companions: stigmatization and discrimination.

By now it does not matter how the stigma started, who first said that HIV was the fate of drug addicts and the promiscuous or who sensationalized HIV as "the plague of the 20th century." The time has passed for arguments about who is to blame, as well as for reproaches and condemnation. The important thing is to realize that the HIV epidemic raging in Ukraine has, by the most conservative estimates of international and national experts, infected 400,000 people, or approximately 1 percent of the adult population. In other words, every hundredth Ukrainian is carrying the human immunodeficiency virus and is at risk for developing AIDS. The more relevant question now is: Can a society ostracize and forget all of these people and still remain a society? The answer is: Likely not. And this is not a question only for Ukraine to ask, but for all the countries of the former Soviet Union and Central and Eastern Europe.

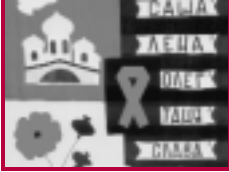
"Since the mid-1990s, HIV-positive persons have been distinguished as a separate cohort of patients in the former Soviet



Local NGOs and service organizations distribute educational information about HIV/AIDS to passersby.

Union because HIV was identified as a particularly dangerous infection," says Svetlana Antoniak, head of the HIV/AIDS Treatment and Care Department of the L.V. Gromashevsky Institute of Epidemiology and Infectious Diseases in Kiev. "From one point-of-view this is correct, but, on the other hand, HIV is not particularly dangerous with respect to the anti-epidemic measures required to quell it. HIV is not an airborne infection. It is not like yellow fever or the plague. HIV is transmitted by contact with blood, semen, vaginal secretions, or breast milk, and strict adherence to protective measures prevents infection."

Antoniak says there are many factors behind the epidemic's rapid spread in Ukraine, but that the main catalyst has been the prevalent laissez-faire attitude toward the problem. "On one hand, people in Ukraine have a kind of mystical reverence toward HIV/AIDS, which is the result of ignorance, fear of the unknown, and fear of something they know can hurt them, although they don't really know how; on the other, they don't completely understand that it's a real danger and that certain



precautionary measures need to be taken by them to avoid contraction. It's like crossing the street without paying any attention to the rules of the road," she explains. "Everybody knows you can only cross the street on a green light and that anybody running across on red is willfully putting himself at risk of all the possible consequences. In the same way, it seems to me that it's about time we established a rational attitude toward the topic of HIV—not being afraid of it or dreading it, but knowing how to behave in order to keep from getting infected," she says, emphasizing that fear is never a good basis for acting rationally and, in the case of HIV, it has only compounded the stigma and discrimination against people who have suffered plenty without that added burden.

People living with HIV know very well the impact of the fear surrounding the disease, as do their relatives and close friends. "The stories of people living with HIV/AIDS (PLWHA) are strikingly similar," says Vladimir Zhovtyak, chairman of the Coordinating Council of the All-Ukrainian Network of PLWHA. "After diagnosis, their status is usually made public and they are denied urgent and necessary medical services. Healthcare professionals justify this type of treatment on the basis of a person's HIV status. Using the same justification, PLWHA are fired from their jobs or kicked out of educational institutions, including kindergartens. If neighbors discover a person's status, life turns into hell for many of them and they are forced to move in an attempt to somehow protect themselves and their families from humiliation and cruelty."

Hearing all the obstacles PLWHA encounter, one wonders how they survive at all. Besides experiencing an acute shortage of antiretroviral drugs and medications for opportunistic infections, Ukraine as a whole has yet to develop a system of psychological support services for these people, which means they are often left alone with their unspeakable pain and distress, in addition to their medical, material, and social problems.

### Disclosure of Status More Terrifying Than the Disease

"I discovered I was HIV-positive 10 years ago," says 38-year-

old Irina, a patient in the HIV/AIDS Treatment and Care Department, sharing her personal story. "I had an ordinary cold and I had a blood test at a local clinic. I found out later that they were testing everybody for HIV. So one fine day a doctor comes to my house and tells me I have HIV and that I have to report to the clinic the next day to give another blood sample so they can confirm the diagnosis. My new life began on that day," she recalls bitterly. Looking at her open face, radiant with vital energy, and her clear eyes, it seems highly doubtful that she could be one of the people everybody is so afraid of.

Irina says there is nothing out of the ordinary about her life story. She lived like everybody else: went to school, graduated from college, got married, gave birth to a son, and got a job as an engineer at a major company in Dnipropetrovsk. Then things began to fall apart between her and her husband and they got a divorce. After the divorce, Irina met another man with whom she fell in love and wanted to spend the rest of her life. Only later did she find out that her chosen was an occasional drug user who was already HIV-positive when they met. She admits that neither the shock of the news nor the pain of knowing the harm her new relationship had caused exceeded the degree of fear that gripped her when she first was told of her status, and has not let go to this day.

"At that moment my brain was completely paralyzed. There were only two thoughts attacking my mind: How will I go to work and what will people say when they find out? That's what was the most horrible for me," confesses Irina. The fear that people would not understand and that she would be persecuted forced Irina to live for several more years with the person who had caused her suffering because at that time she could only be open about her diagnosis with him.

"Ten years ago, the public's attitude toward HIV-positive people was even worse than it is now. At that time, all people with HIV were pariahs. Very little was known about the disease itself. Treatment was out of the question and the doctors said I had a maximum of five years to live," explains Irina. "The most

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unpleasant memory from this entire episode is the attitude of the epidemiologists. They conducted humiliating interrogations about my past, trying to dig up something negative. The whole time, their attitude was contemptuous, as if they no longer considered me a human being,” she says, trying to swallow a lump in her throat while closing her eyes tightly to prevent herself from crying. The next moment she shakes her head fighting back the memory and continues, saying that there is one thing in the whole story that was very fortunate—medical confidentiality was not violated in her case, which meant that people where she works and at the school her son attends do not know her status. Still, all these years she has lived in constant fear of the thought that it will be revealed some day.

### Discrimination Within the Healthcare System

For 25-year-old Olga, another patient at the same facility, her story began 10 days prior to her wedding. A few weeks before, Olga had discovered she was pregnant and went for an ob/gyn exam at the local outpatient clinic where a number of tests done on all pregnant women in Ukraine—including an HIV test—were performed.

“I live in a village where everybody knows me and my family, so the doctor who told me about the positive result of my HIV test was sure it was a mistake,” says Olga. But it turned out later that there had been no mistake. The real mistake, Olga says, was her first love, a young man she met at school who was a secret drug user. Olga only learned about his addiction after she found out about her own status. “My fiancé and I could not believe it. Where could it have come from?” we asked ourselves. When my future husband tested negative, it became clear who had to be the source; before I met my husband, I had relations only with one man.”



Photos: Vira Illiesh.

A family pays their respects to a loved one lost to the HIV/AIDS epidemic at Kiev's Red Ribbon Monument.

Olga and her fiancé got married anyway, but they didn't stay together long because they could not overcome their own fears and the pressure from other people. “Unfortunately, we were not given any information on the nature of the disease or its transmission routes, so we didn't know what to do in our situation,” Olga recalls. She says that her husband would clean himself with alcohol after they had intimate relations and was afraid to come near their daughter when she was an infant. “I am sure that if the doctors had really explained things to us, we would have been able to avoid getting divorced. What drove us apart, really, was a fear of something we didn't know anything about!”

It is clear from Olga's story that the pediatrician at the local outpatient clinic did not really know anything about the disease either. “For the first 18 months of my daughter's life, none of the local doctors wanted to provide her with any medical care. I had to

take her to the regional AIDS Center. When I asked at the rural outpatient clinic why nobody would treat my baby, the pediatrician replied that she didn't know what to do with her.” And that doctor evidently had never heard of the concept of medical confidentiality, which it is against the law to violate. “One time she passed the message along through my neighbor that my daughter should have a repeat HIV test,” Olga recalls. “This news drove all my neighbors into a wild state of horror and I had to give them explanations and tell them all sorts of nonsense to keep them from shunning me.”

Even after the baby was confirmed to be HIV-negative and was removed from the AIDS Center's roster, Olga says the local pediatrician continued to be afraid of the child and never missed a chance to ask again in disbelief—including in front of strangers, “Are you sure she doesn't have HIV?”



The local pediatrician was not the only local healthcare worker lacking reliable information about the transmission of HIV, not to mention medical ethics. There were other “professionals” like this. By an unfortunate coincidence, the midwife who helped Olga’s doctor during her Caesarean section turned out to be an acquaintance of a friend of Olga’s. Seeing Olga and her friend together, she made sure to tell Olga’s friend what kind of person she was associating with. “She told her that my baby and I both had AIDS and would soon be dead,” Olga exclaims with indignation. “I don’t know how she remembered me, but she told my friend to keep away from me and to wash everything down with bleach after I had been there. She also told her that AIDS can be transmitted by mosquito bites and casual contact, so that on no account should our children play together.” This time, Olga decided not to remain silent, but to sue the woman who was breaking the law. She said that ultimately the matter did not reach a courtroom, because after Olga paid a visit to the offender’s place of work, the incident was quickly hushed up. The woman told Olga’s friend that she had mixed everything up and that Olga was absolutely healthy.

What is amazing about this story, is how carelessly some healthcare professionals treat the lives of their patients. Instead of using their knowledge to help root out the stigma, they sometimes promote it, as Sergei’s story bears out.

Sergei is 27 years old. He says he was never a drug addict nor a Don Juan, but that he works as a physician’s assistant and most likely contracted HIV at work. “On occasion I had contact with blood while doing my job,” he explains. “No healthcare worker is absolutely protected against this happening, but it’s quite another matter that I had no idea what the result of doing so might be.”

Now Sergei is a patient at the HIV/AIDS Treatment and Care Department. He reports encountering discrimination against PLWHA, such as when he needed to consult a specialist. “They suspect that I have a brain tumor, but in order to prescribe the right treatment I need to see an oncologist,” he explains. When Department doctors appealed for help to the Consultation Clinic at the Oncology Institute of the Ukrainian National Academy of Sciences, the relevant services were denied because of Sergei’s HIV status, which means he has no real prospect of being prescribed appropriate treatment. In the meantime, the young man’s condition is irreversibly deteriorating. While in the

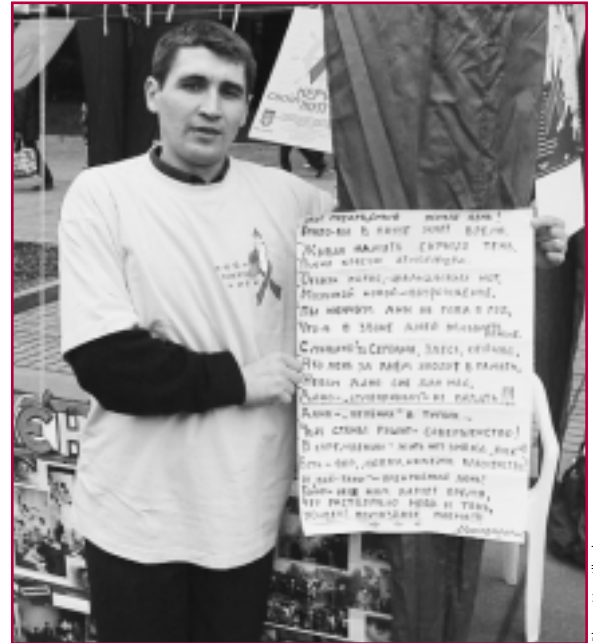


Photo: Vira Illiach.

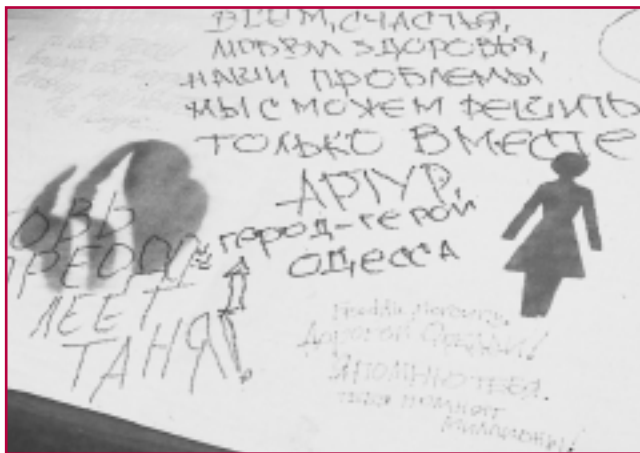
A member of the All-Ukrainian PLWHA network displays a poem he wrote in honor of the Day of Remembrance. It begins: “This wonderful sunny day; It seems like time pauses and waits; Memory of this day hides shadows of the past; The atmosphere is beautiful.”

recent past he was still able to go outside on his own, now he is limited to moving with great difficulty inside the facility.

Staff members from the Chas Zhittya Plus charity are advocating on Sergei’s behalf, trying to get him diagnosed at the Oncology Institute. Chas Zhittya Plus was established by a group of HIV-positive individuals dedicated to standing up for the rights and interests of PLWHA, as well as to provide mutual psychological support. The organization’s president, whose name is Anatoliy, explains that the Oncology Institute has still not agreed to provide the care needed by Sergei despite numerous requests and appeals from Chas Zhittya Plus members to the Clinic’s leaders. According to Anatoliy, the clinic not only refuses to examine the patient, but does not even want to look at the results of tests done on Sergei” justifying this refusal with negative attitude towards HIV-positive persons, which they don’t even attempt to hide.”

### Legislative Protection and Comprehensive Education

Svetlana Antoniak says that Sergei’s case is not the only instance of this kind of attitude that she has heard about. The department she heads is only staffed by infectious disease specialists, but the number of patients requiring consultations with more specialized physicians is rising each year. “Despite



On the Day of Remembrance, people share their feelings about HIV/AIDS and write tributes to those whose lives have been lost to the epidemic on a Memory Banner.

the existence of a number of healthcare institutions that are required by law to provide medical and diagnostic services to HIV-positive patients, the directors of these institutions want nothing to do with PLWHA, believing that using diagnostic instruments and apparatus on them will irreversibly contaminate the equipment,” she says.

On the surface all of this appears to be absurd, especially considering that Ukraine has a law On AIDS Prevention and Social Protection for the Population, Article 18 of which prohibits the denial of any medical care to persons living with HIV, while Article 19 of the same law establishes legal answerability for infringing the rights of this specific group of people. According to Antoniuk, however, this and other Ukrainian laws concerning HIV are generally treated as merely declarative. “We have repeatedly attempted to analyze the legislation related to HIV and the rights of infected persons. We have concluded that these laws are essentially ‘dead,’ because they are not backed up in judicial practice,” she explains, stressing that it is not easy to achieve in real life what would seem to have been set down so definitively by the legislative branch of government.

“At the same time,” Antoniuk continues, “as a rule, HIV-positive persons do not rush to the courts in an attempt to stand up for their rights because they are afraid their status will be publicized even more widely. In addition, there are a lack of lawyers with adequate experience in defending the rights of PLWHA.” As a result, she asserts, “our patients understand that they have a slim chance of winning and a rather greater chance of incurring additional

expense, suffering, and humiliation.” Asked to comment on this situation, the Director of the Ukrainian Center for AIDS Prevention Alla Shcherbinskaya explains the problem of HIV stigmatization as chiefly a reaction to the ordinary population’s deeply ingrained stereotype of the negative behaviors with which transmission of this disease is associated.

“None of us can pass judgment on a sick person, especially when each infected individual is so different and among them are people who are not at all culpable in their becoming infected. Therefore society must learn to approach this problem as a disease, without shame and condemnation. It has to be realized that PLWHA need treatment and moral support. In order to achieve this, we have to radically change our attitude because the number of HIV-positive people in Ukraine is rising. They include children who will soon be going to school and whom it is crucial to bring up as psychologically healthy, full-fledged citizens of our country,” says Shcherbinskaya, emphasizing that this can only be achieved through mass education of the population on HIV transmission and prevention.

“Every inhabitant of Ukraine should know how HIV is transmitted in order to protect themselves and their families, as well as to alleviate their fear of infection, which is based on ignorance. This is the only way to eliminate the stigma that this fear produces,” she says with conviction. Shcherbinskaya emphasizes that this education of the population should be carried out at many different levels, including through mass media information campaigns and targeted lessons and briefings in schools, at workplaces, and even at residential housing offices. “People need to be educated everywhere because HIV infection is a shared problem that may affect anybody. To protect oneself and make it possible for those who are already infected to live, a great deal of knowledge is needed. Therefore, I call upon everybody to start using common sense. Don’t recoil at the word ‘HIV,’ but act right!” she stresses.

Despite all the difficulties now being experienced by PLWHA, some positive changes have begun to be noticed in Ukraine, such as the fact that preparations are under way in the country to introduce antiretroviral therapy on a large scale. A few years ago, treatment was not even considered and PLWHA reported that nobody even wanted to admit that the problem of AIDS existed, though nearly 4,000 Ukrainian citizens have died from the disease since 1987.



Now the problem is under discussion at the highest level, in the Ukrainian Parliament. Programs are being developed and implemented in the country, not only to prevent HIV, but also to treat AIDS and associated opportunistic infections. There is ongoing, targeted training of the specialists who will administer antiretroviral drug regimens and protocols for treatment and laboratory testing to monitor HIV disease are being developed and implemented.

More and more frequently, Ukrainian politicians talk about the need to change certain points of law that would ensure appropriate respect for the rights of PLWHA, while at the same time restricting the potential for them to be discriminated against or ostracized. More and more frequently, Ukrainian pop music stars and popular TV and radio announcers have begun to defend the rights of HIV-positive persons, educating youth in a low-pressure way about how the disease is transmitted and how to prevent it.

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Even the Orthodox Church, which until quite recently viewed HIV as something “unwanted by God,” is now attempting to inform its members about the problem, realizing its urgency for civil society. This about-face is evidenced by the material about HIV published in the latest issues of the Kiev-Pechersk Laura Information Center’s bulletin, *Vestnik*.

These changes have largely come about thanks to the efforts of HIV-infected people themselves, as well as the NGOs and international organizations that are fighting HIV in Ukraine. What is most important is that the ice has been broken. What other explanation can there be for a person living with HIV to say during the May event that lately there have been more sunny days in his life?

“What about the wind?” I asked. “Let it blow,” he answered with a laugh, “as long as it doesn’t let the clouds cover the sun.”

“That’s how it is,” I thought, looking at the sky, and told myself it was a good omen. Whether or not I was right, time will tell. ■