

Natalia A. Feduschak, a Kaiser International Fellow and a freelance journalist, wrote and delivered the following lectures about HIV/AIDS to journalism students at the Kyiv National Taras Shevchenko University and Kyiv International University between April 2005 and November 2006. The lectures are based on her own research and interviews conducted in Ukraine and Europe, through resources provided by the Kaiser Family Foundation, Transatlantic Partners Against AIDS, numerous Ukrainian non-profit groups and the experiences of people living with HIV/AIDS.

Lecture 1: Overview of HIV/AIDS Globally

HIV/AIDS is one of the most important social, political and health issues affecting Ukraine today. Despite its importance, however, the subject remains far from society's consciousness and is still not adequately covered in the Ukrainian media. The stories that do appear are often dry, consisting of statistics that mean little to the reader, or do not approach HIV/AIDS in a way that makes the issue pertinent to people's lives.

The purpose of this course is two-fold: to convince young journalists that HIV/AIDS merits consistent and in-depth reporting, and to give them the tools to do so. Over the next five weeks, we will look at the HIV/AIDS situation globally, regionally, and in Ukraine. In addition, we will discuss important related issues, such as HIV/AIDS as a national security issue, access to medication and the link between TB, alcoholism and HIV/AIDS. Finally, we will discuss source development and the ethics and professionalism of reporting on HIV/AIDS.

Our reading materials will be varied, consisting of a handbook on reporting about HIV/AIDS, which was written by the Kaiser Family Foundation, a private U.S. non-profit organization that works in the health field, and which was translated into Ukrainian. Contributing to the handbook is Transatlantic Partners Against AIDS, an international non-government organization that works with politicians in Ukraine and Russia to curb the rise of HIV/AIDS. We will read articles that have appeared in Ukraine and the

United States on topics related to HIV/AIDS, as well as excerpts from books that have been published in the U.S. In class, we will discuss articles, potential ethical dilemmas when reporting on HIV/AIDS and how to resolve them, and brainstorm potential story ideas.

The summer of 2006 marked the 25th anniversary since scientists identified a “mystery” illness affecting thousands of people around the world. Although scientists believe HIV was present in humans many years before the first case was brought to public attention in 1981, by all accounts, HIV/AIDS is proving to be the worst human disease catastrophe in history.

Many people have equated HIV/AIDS to the Black Death that plagued Europe in the 14th century, where an estimated 25 to 30 million people out of a population of 75 million died between 1346 and 1350. The casualties of HIV/AIDS, however, are outnumbering those of the Black Death plague and are proving even more catastrophic: In the last quarter of a century, more than 25 million people have lost their lives to AIDS and related illnesses. That, experts say, is more than all of the casualties of the 20th century’s wars combined and it is only a matter of time that “HIV/AIDS will claim more lives than all the wars in history put together,” writes Susan Hunter, a consultant to international organizations in her book, *Black Death: AIDS in Africa*. Over 149 million people have perished in wars since the first century,

Since the virus was discovered, 65 million people have acquired HIV, while 39 million people are currently living with the virus. In what are considered to be “next wave” countries -- Nigeria, Ethiopia, India, China and Russia – the number of people living with HIV in these five countries alone is expected to reach 75 million by 2010.

John Stover of the Futures Group and co-author of the study *The Global Impact of Scaling-Up HIV/AIDS Prevention Programs in Low- and Middle-Income Countries*, estimates that if current trends continue, there will be about 60 million new infections of HIV among adults and children between 2005-2015. With rapid and comprehensive expansion of prevention programs, however, that number could drop in half, with 30 million new infections in the same 10-year period, Stover and his colleagues estimate. In their report, they also write that preventing new infections would require investing about \$122 billion over the 10-year period, a substantial sum, but one that would reduce the future need for treatment and care.

Kaiser's handbook has a timeline of the milestones of the HIV/AIDS epidemic both globally and in Ukraine. Additionally, there is a section about the pandemic's trends globally, which gives you an idea of where and what parts of society are being affected. Pay particular attention to the segments of society that are being hardest hit by HIV/AIDS today – young people and women. The effect is that as these segments of the population face living with HIV, the economies and societies at large suffer.

The situation in Ukraine today mirrors what is happening to many developing countries around the world. Unfortunately, Ukraine's HIV/AIDS rate is one of the world's fastest growing; international organizations estimate that currently 1.4 percent of the adult population is HIV-positive. We will discuss the situation in Ukraine next week, as well the challenges the country faces in curtailing its epidemic. The situation at home will also give us a better idea of how HIV impacts other societies.

Some history: Before it became a global pandemic, HIV barely captured the public's attention. It was only through the work of a dedicated group of scientists who,

after hearing about a mysterious illness that was affecting not only gay men in the United States but heterosexual people in Africa as well, convinced public officials the new illness was a truly global phenomenon.

The U.S. Centers for Disease Control and Prevention, which is an arm of the U.S. Department of Health and Human Services, formally coined the term Acquired Immune Deficiency Syndrome (AIDS) in 1982. The CDC referred to four “identified risk factors” for the illness – male homosexuality, intravenous drug use, being of Haitian origin and hemophilia A. Two years later, in 1984, the HIV virus was isolated by Luc Montagnier of the Pasteur Institute and Robert Gallo of the National Cancer Institute. The virus was later given the name it now carries – the Human Immunodeficiency Virus, or HIV.

The reaction to the HIV/AIDS pandemic – particularly in the U.S., which has taken the global lead on funding and research of HIV/AIDS -- can generally be broken down into the following timeframes:

The 1980s: A period of fear. The effect of and scope of HIV/AIDS was still unknown. Many homosexual men were dying in the U.S. while African nations were seeing an upsurge of heterosexual people perishing because of the virus.

The late 1980s and early 1990s: A difficult period as HIV/AIDS began to take a devastating toll. A variety of and viability of treatments for HIV were being explored.

The mid- and second-part of the 1990s: A time of euphoria. HAART, the highly effective antiretroviral therapy, was introduced. But there was also a realization that HAART was not a cure and that other treatments were needed.

An important moment in understanding the virus came in 1999, when, after nearly two decades of debate over the origins of HIV, scientists discovered the virus began in

the chimpanzee and had “jumped” to humans. Scientists had known that non-human primates carry their own version of HIV, which is called simian immunodeficiency virus, or SIV.

Scientists, which include Paul Sharp of the University of Nottingham in England and Beatrice Hahn of the University of Alabama-Birmingham, believe HIV originated in wild chimpanzees, most likely in a corner of the African nation of Cameroon.

Presumably someone in rural Cameroon was bitten by a chimp, or was cut butchering one, and became infected with the ape virus. That individual then passed it on to someone else. Eventually, the virus ended up in urban areas, where it then rapidly spread. The prestigious journal *Science* (www.sciencemag.org) is one of several magazines that have published scientific findings related to HIV/AIDS over the years.

Finding out the origins of HIV is important because if scientists can determine how chimps live with the virus without getting sick, that knowledge could be applied to humans. There is only a 1.5 percent difference between humans and chimps in DNA. Still, there is no known cure for HIV/AIDS; attempts at finding a vaccine against it have thus far proven fruitless.

Since 2000, the focus has been on the global pandemic. There is now an understanding that HIV/AIDS is a development issue and is intrinsically linked to poverty, a lack of education and knowledge about the virus. On a larger scale, it also affects a country’s national security, the stability of a nation’s work force, its demographics, and political and economic structures.

That does not, however, mean that HIV/AIDS is a problem in only developing countries. In the U.S., for instance, HIV has hit the African-American community very

hard in recent years. While there are many reasons for this, one is the high prevalence of black men who live in the “down-low”, i.e., men who have sex with other men without their female partners being aware of the practice.

Despite years of steady stability or decline, European countries are again seeing an increase in the number of cases of HIV, although many of these involve immigrants from the developing world. Again, the issue is development, education and economics.

The year 2000 brought about several important events, including the 13th International AIDS Conference, which was held in Durban, South Africa. This was the first time that the conference, which annually brings together scientists and advocates, was held in a developing country. (Emphasizing that HIV/AIDS had become a truly global problem, in 1999, U.S. President Bill Clinton established LIFE – the “Leadership and Investment in Fighting the an Epidemic” initiative – to address the *global* pandemic.)

In 2001, the United Nations General Assembly convened its first-ever special session on AIDS. This was a milestone event in the global fight against HIV/AIDS. The assembly laid out a host of challenges, including getting life-saving medications to those who needed it by 2005. (Dubbed the 3x5 Initiative, the goal was to get three million people on antiretroviral treatment, which was not everyone who needed medication, but was an important step forward in providing drugs. The initiative failed to meet its stated goal, although there was progress in expanding treatment globally.)

Later that year, Kofi Anan, the U.N. Secretary General, called for a “war chest” to fight AIDS, and the World Trade Organization announced the “DOHA Agreement” which allowed developing countries to buy or manufacture generic medications to meet public health crises, such a HIV/AIDS. That same year, Colin Powell, who was U.S.

President George W. Bush's Secretary of State, reaffirmed that HIV/AIDS was a national security threat.

Other milestones since 2000 include:

- The creation of the Global Fund to Fight AIDS, Tuberculosis and Malaria, which started operating and provides grants worldwide;
- HIV became the leading cause of death worldwide among those aged 15-59, while UNAIDS reported that women comprise half of all adults living with HIV/AIDS worldwide.
- U.S. president George W. Bush announced PEPFAR, the President's Emergency Plan for AIDS Relief. PEPFAR is a five-year \$15 billion initiative to address HIV/AIDS, tuberculosis and malaria primarily in hard-hit countries.
- Phase I of a human vaccine trial was launched in South Africa in partnership with U.S. in 2003.
- The 15th International AIDS Conference was held in Bangkok, Thailand, the first such conference held in Southeast Asia.
- The U.N. General Assembly held a follow-up meeting to its 2001 special session on HIV/AIDS to review progress on targets. "HIV/AIDS constitutes a global emergency and one of the most formidable challenges to human life and dignity, as well as to the effective enjoyment of human rights, which undermines social and economic development throughout the world and affects all levels of society-national, community, family and individual," the U.N. said.
- Russian President Vladimir Putin, in his 2003 Annual Address to the Federal Assembly, described declining life expectancy as a serious threat to Russia's future. He said "AIDS is making it worse."
- The William J. Clinton Presidential Foundation secured price reductions for AIDS drugs from generic manufacturers. Ukraine is one of the countries that will benefit.
- An estimated 700,000 people received antiretroviral drugs by the end of 2004, although Kofi Annan admitted despite stepped up efforts globally to curb the spread of HIV, society was still losing the battle against it.
- UNAIDS launched The Global Coalition on Women and AIDS in 2004 to raise the visibility of the epidemic's impact on women and girls around the world.
- At the 2005 World Economic Forum's Annual Meeting in Davos, Switzerland, priorities included a focus on addressing HIV/AIDS in Africa and other hard hit regions of the world.
- At a historic and unprecedented joint press conference in 2005, the World Health Organization, UNAIDS, the United States Government and the Global Fund to Fight AIDS, Tuberculosis and Malaria announced results of joint efforts to increase the availability of antiretroviral drugs in developing countries.
- In 2005 almost 39 million people worldwide are living with HIV, according to UNAIDS estimates.
- In 2006, the United Nations convenes a follow-up meeting to assess progress related to the historic 2001 Declaration of Commitment on HIV/AIDS, while the

- first Eastern European and Central Asian AIDS conference (EECAAC) was held in Moscow.
- The 16th International AIDS Conference was held in Toronto, Canada in August 2006. The conference's theme, "Time to Deliver," underscored the continued threat of HIV/AIDS and the need of nations to honor financial, programmatic and political commitments to prevention and treatment of HIV/AIDS.
 - June 5, 2006, marked a quarter century since the U.S. government issued its first warning about a disease that would become known as AIDS.

From the beginning, nations have responded to the pandemic in different ways. In part, that is because HIV initially affected different segments of the population. In Africa, for instance, which has thus far borne the brunt of the HIV/AIDS crisis, transmission of the virus has been mostly through heterosexual contact. In the U.S. and other western nations, the virus first made its appearance in the homosexual community, and then spread to other segments of the population. Public perception of whether people were "worthy" members of society also played a role in how quickly and to what extent governments responded. Public perceptions have also effected how citizens have, and in some cases, continue to view their own national epidemics.

In his book, *Invisible People: How the U.S. Has Slept Through the Global AIDS Pandemic, the Greatest Humanitarian Catastrophe of Our Time*, Greh Behrman writes that Zaire, for instance, was willing to allow Western researchers conduct their work in trying to identify a mystery illness that was affecting many Africans, but officials were upfront about saying they were unable to provide assistance. They had too many other problems to worry about. As an example, Behrman describes the first meeting between Dr. Joe McCormick, one of the earliest AIDS researchers from the United States and the Zairian health minister.

The year was 1983 and McCormick had just arrived in the Congolese capital of Kinshasa on a six-week investigation sponsored by the U.S.'s CDC to look into a virus

that had similarities to AIDS in the United States. (Indeed, the first human known to have had the HIV virus was a man from Kinshasa, who had his blood stored in 1959 as part of a medical study, decades before scientists knew HIV existed. Do you need a source for this?)

By the time of McCormick's visit, the CDC had reported its 1,000th case of AIDS in the U.S. and the disease was growing at an alarming pace:

“The next day, McCormick met with Zaire’s health minister Dr. Tsibas, a tall man with graying hair who cut an elegant and somewhat reserved figure. McCormick’s reception was cordial, but stern. Tsibas asserted that existing health issues – including malaria, malnutrition, diarrhea, tuberculosis, sleeping sickness, and measles – were already overwhelming the national health system. He would be happy to cooperate, but he warned in polished French, “Don’t count on finding much interest or support from us for the problem you are interested in... We can’t even cope with the ordinary problems I just told you about.” (Pg. 8)

McCormick's results were alarming, writes Behrman. After their return to the U.S., *“the team had demonstrated that AIDS had secured an ominous foothold in Africa. Most notable of the findings was that the disease was transmitted almost entirely through heterosexual contact in Africa. It had obvious ramifications for the burgeoning U.S. epidemic. It also meant that AIDS wasn’t an issue for subpopulations in Africa – the entire population was vulnerable. The worst-case scenario was imponderable. McCormick and his colleagues, it seemed, had discovered a pandemic in its nascence.”* (Pg. 11)

Yet AIDS activists in the United States were decrying their government's response to the HIV/AIDS crisis. Although the U.S. Congress held its first hearing on HIV/AIDS in 1982, it was not until 1987 that Ronald Reagan, the U.S. president at the time, mentioned the word "AIDS" in public. Even then, when the HIV/AIDS crisis could no longer be ignored, critics say rather than engage his administration in implementing a comprehensive HIV/AIDS policy, the conservative president emphasized abstinence. A Reagan aide, Behrman writes, even proposed "the sequestration of AIDS patients in the U.S." (Pg. 28).

Activists say part of the initial reluctance by U.S. government officials to acknowledge the virus was largely because HIV was so prevalent among the nation's homosexual community. Indeed, in its early coverage of the virus, the U.S. media initially referred to it as "GRID" or "gay-related immune deficiency", a term that was loaded with stereotype and stigma.

Behrman writes that for the Reagan Administration "*AIDS had become a political hot potato and the Reagan Administration's strategy, to the extent there was one at all, was to avoid it. The subpopulations suffering in the United States were not part of Reagan's constituency. AIDS was sexuality and death: not the stuff that politicians are wont to gravitate toward. If the disease was truly heterosexual, then it was a bigger problem (at least politically) than the administration had estimated. They would have to address it, and they didn't want to do that unless they had to.*" (Pg. 12)

However, the death of his friend, the popular American actor Rock Hudson, in 1985 from AIDS did motivate President Reagan to support more active measures to contain the spread of HIV/AIDS. In 1987, he created the President's Commission on the

HIV Epidemic, also known as the Watkins Commission. In one of its reports, writes Berhman, “the council pointed the administration to the global dimension of the disease, and suggested that early engagement would be critical.”

The commission was succeeded by a permanent advisory council, and subsequently, under President Bill Clinton, by the so-called AIDS Czar. Discretionary spending by the Federal government on AIDS research programs for both prevention and treatment increased steadily during Reagan's two terms in office.

Individuals involved with HIV/AIDS say that particularly in the United States, the label of HIV being a gay disease sticks to this day. Some critics argue even though separate religious individuals were active, the Church as a whole (experts on religious affairs and HIV say it is not just the Catholic Church, but many other faiths as well) was reluctant to be more involved in the HIV/AIDS crisis in the U.S. is because of moral issues related to homosexuality. Indeed, even though currently over one million people in the U.S. are HIV-positive, some experts working in the field allege that the U.S. is more interested and active in curbing the pandemic internationally than dealing with the issue at home. However, the U.S. has been taking the lead on anti-AIDS funding; the current Bush Administration is devoting more financial resources to HIV/AIDS than any other U.S. administration.

A principle challenge for developed countries was how to handle the HIV/AIDS pandemic. With HIV, developed countries took widely different approaches, often contradictory to what they had historically done, regarding communicable diseases and epidemics, according to Peter Baldwin, a professor of history at the University of

California, Los Angeles. He explains those differences in his newly published book *Disease and Democracy: The Industrialized World Faces AIDS*:

“Cholera victims used to be quarantined. Lepers were compulsorily institutionalized well into the twentieth century. Syphilitic prostitutes were once, and sometimes continue to be, locked up and forcibly treated. In many countries they were registered with the police and had to show up for periodic inspections. In sum, it was common to violate the civil rights of the ill to spare the still healthy. By this standard, an exception was made for AIDS. Public health authorities believed that, in the late twentieth century, you could no longer order the ill to act in certain ways or restrict their liberties. Instead, educational campaigns sought to convince citizens to change their behavior voluntarily to make them less vulnerable to infection.

“...Western nations took widely different approaches to the common problem of the AIDS epidemic. Some countries sought a cure, hoping to avoid the tricky politics of imposing behavioral structures on powerful high-risk groups or to sidestep drastic statutory impositions that were incompatible with other political traditions. In other countries the state was allowed a nearly free hand in limiting individuals rights on behalf of overall epidemiological security. Some saw the threat as coming from without, and imposed controls at the borders. Others recognized frontier patrols as fruitless and staked their hopes on domestic interventions. Some shied away from making uniform recommendations about nontransmissible behavior to a multicultural population of variegated customs, habits, and morals. Others were confident that implicit national norms of conduct could be relied on to guide behavior. Even more interesting, which nations took which approach was rarely intuitively obvious. Countries commonly

considered to be laissez-faire (the United States) and concerned with civil rights (Sweden) took the most old-fashioned and restrictive approach. Others with traditions of statutory initiative that were longer (France) and sometimes drastic (Germany) were markedly hands off.” (Pg. 2)

The challenge for the industrialized world in public health, writes Baldwin, has been how to balance the rights of society and individuals who are affected by communicable diseases. That challenge is one that other less-developed nations will face as the pandemic grows:

“Illness, in the best of circumstances as private misfortune, becomes public and political. How is the infectious patient to be treated? Much depends, of course, on the disease in question: whether transmissible via mere proximity, as with tuberculosis and smallpox, or whether limited to deliberate, usually voluntary and purposive contacts, like syphilis or AIDS. Requiring isolation and possibly treatment makes sense in the former case yet seems less persuasive in the latter. But how to deal with contagious disease is more than a technocratic public health matter. Basic political decisions are involved. How much protection the rights of the afflicted citizen? Where should the line run between the imperatives of the group and the liberty of the patient?”

“It seems intuitively plausible that different political systems, varying ideologies and cultures, do not answer such questions uniformly. What is the same biological problem in each polity – infections with a particular microorganism – might be dealt with in quite different ways. The AIDS epidemic in the developed world presented much the same challenge in each nation. True, the epidemic manifested itself differently in various countries, especially afflicting gays in some, drug injectors elsewhere, hemophiliacs in

yet others, or heterosexuals across the boards, as in the Third World. It was spread via blood donations in China, drug injections in the Mediterranean, homosexual sex in America, and heterosexual intercourse in Africa. Moreover, there were various strains of human immunodeficiency virus (HIV) whose differences had epidemiological repercussions. Some were more infectious and readily transmissible through heterosexual intercourse. Others were passed more via needle sharing, unprotected anal sex, and other forms of potential blood contact. Nonetheless, in broad terms, the problem was much the same for each polity of the industrialized world.” (Pp. 8-9)

A quarter of a century after HIV first made its appearance, the world has not seen the worst of its effects. Countries continue to react to the pandemic in different ways. Some approaches have been more successful than others. African governments are overwhelmed by HIV/AIDS; Asia is at the beginning of its pandemic. Western nations, because of better access to treatment for those who need it, see a more controlled situation, although there are segments of the population who are at higher risk. Next week we'll take a look closer to what is happening at home, and in Ukraine's back yard.

Reading:

1) Sections from the Kaiser Reporting Handbook:
HIV/AIDS Terminology, Glossary pp. 1-11
Frequently Asked Questions, pp. 25-27
Timeline (International and Ukraine), pp. 18-24
HIV/AIDS in the World and Ukraine, pp. 12-17
Country Experiences with HIV/AIDS, pp. 69-71

2) UNAIDS 2006 Global Report Executive Summary 2006
LINK: http://data.unaids.org/pub/GlobalReport/2006/2006_GR-ExecutiveSummary_ru.pdf

3) UNAIDS 2006 Global Report, Overview of the Global AIDS Epidemic
LINK: http://data.unaids.org/pub/GlobalReport/2006/2006_GR_CH03_ru.pdf

4) Series on HIV/AIDS in *The Day* newspaper.

ВІЛ-загроза, Чи зуміє Україна використати досвід Заходу,

№131, вівторок, 8 серпня 2006

LINK: <http://www.day.kiev.ua/166763/>

Притулок матері Терези,

№189, четвер, 2 листопада 2006

LINK: <http://www.day.kiev.ua/171590/>

ВІЛ/СНІД: шляхи подолання, Програми інтервенцій наркозалежних реально
приводять до скорочення кількості нових заражень

№211, субота, 2 грудня 2006

LINK: <http://www.day.kiev.ua/173434/>

«Назарет» під Дрогобичем

№225, вівторок, 6 грудня 2005

LINK: <http://www.day.kiev.ua/153832/>