## **Connections**

#### June 2005

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#### **Partner News**



## **Successful PMTCT Strategies Provide Basis for Development of National Programs in Central Asia**

According to the US Centers for Disease Control and Prevention (CDC), mother-to-child transmission (MTCT) of HIV accounts for nearly 90 percent of the more than 600,000 estimated new HIV infections that occur among children worldwide each year. Without intervention, there is a 15-30 percent risk that an HIV-infected mother will transmit the virus to her child during pregnancy or delivery and an additional 10-20 percent risk of transmission if she breastfeeds.

In Central Asia, the actual number of registered HIV/AIDS cases is low in comparison to Russia and Ukraine, although the rate of new infections is increasing

at an alarming pace. The reality of the region's epidemic today is that more and more women—particularly those in their reproductive years—are contracting the virus through sexual contact. In Kazakhstan alone, this mode of transmission has increased five-fold within the last four years, threatening the health of future generations. National experts believe that while the epidemic in Central Asia is still in its early stages, prevention of mother-to-child transmission (PMTCT) of the virus should become a key element in their strategy to combat HIV/AIDS.

International strategies and programs that have proven effective in decreasing MTCT in Europe and other countries of the former Soviet Union were showcased during a conference conducted March 1-3 in Almaty, Kazakhstan, by AIHA in close collaboration with the World Health Organization (WHO) and the United Nations' Children's Fund (UNICEF), and with financial support from the United States Agency for International Development (USAID). The "Regional Conference on the Prevention of HIV Infection in Infants in CAR" provided a forum for key government officials, policymakers, public health professionals, and care providers from Kazakhstan, Kyrgyzstan, Tajikistan, and Uzbekistan as these countries struggle to



Ruslan Malyuta, WHO/EUROPE medical officer of child and adolescent health development, answers questions from the audience while Sanjiv Kumar, UNICEF regional program officer for health and nutrition, Arun Gupta, coordinator of IBFAN Asia Pacific Regional Program, Bekbai Khairullin, chief pediatrician of Kazakh Ministry of Health, and Jim Smith, AIHA's executive director, look on. (Photo courtesy of Assel Terlikbayeva.)

create effective national prevention programs. Leading HIV/AIDS experts from the United States and international organizations including UNAIDS, CDC, the United Nations Population Fund, the Drug Demand Reduction Program, AIDS Foundation East-West, Project Hope, and other scientific and donor organizations also participated in the event.

The conference—which was facilitated by PMTCT and HIV/AIDS training specialists from AIHA, WHO, and UNICEF—provided attendees with an overview of WHO and UNICEF strategies for the Prevention of HIV Infection in Infants in Europe and Central Asia and set the stage for national policymakers to talk about existing PMTCT policies and interventions in CAR. More importantly, it laid the groundwork for regional scale-up efforts that will extend the reach of AIHA's highly effective PMTCT model beyond the four Kazakh pilot sites where it was first implemented in the region in 2003.

## Laying the Groundwork for Implementation of International Prevention and Care Standards

Describing the core principles of WHO's strategy for helping European and Central Asian governments meet globally adopted benchmarks in PMTCT, Ruslan Malyuta, WHO/EUROPE medical officer of child and adolescent health development, underscored the importance of establishing comprehensive prevention, care, and treatment services that would emphasize counseling and testing, as well as integrating HIV/AIDS-related prevention and care services into the maternal and child healthcare (MCH) system. He stressed that for this strategy to work, national protocols on testing and counseling must be developed, clinical specialists must

receive extensive training, all medical and non-governmental agencies involved in service delivery to people living with HIV/AIDS (PLWHA) must cooperate and effectively integrate their various programs.

Following Malyuta's presentation, Sanjiv Kumar, UNICEF regional program officer for health and nutrition, described the basics of the Strategic Framework for Prevention of HIV infection in Europe and its progress in CAR. The main goal of this Framework is to assure that by 2010 only one HIV-positive infant is born per 100,000 live births. According to Kumar, this can be attained if two key underlying objectives are achieved: integrating information, counseling, and other HIV prevention services into the primary healthcare system and ensuring that at least 80 percent of all women have access to these services.

Kumar went on to say that while almost all countries in CAR offer preventive therapy during pregnancy and post-partum, prevention of HIV infection in the general population of women is unfortunately overlooked. Underscoring the fact that prevention of HIV in women and girls is the surest way of avoiding transmission of the virus to infants, he named three other elements that are paramount in addressing vertical transmission and combine with the first to form the foundation of WHO's four-pronged approach: prevention of unintended pregnancies among HIV-positive women; use of efficacious antiretroviral drugs and specific clinical procedures to prevent vertical transmission; and comprehensive healthcare services specifically designed for HIV-positive women, their newborns, and their families.

In another presentation, speakers from the ministries of health of Kazakhstan, Tajikistan, Turkmenistan, and Uzbekistan highlighted their national PMTCT policies, services, and interventions, revealing some similar tendencies related to the HIV/AIDS epidemic in general and PMTCT efforts in particular. Approximately 60 percent of the population in these countries lives in poverty—a phenomenon that has significantly contributed to substantial yearly increases in injecting drug use and the commercial sex trade. Although the overwhelming majority of people living with HIV/AIDS in these countries are male drug addicts, the proportion of women affected by the epidemic is steadily growing and has reached an average of 20 percent of the total. Most of these women belong to vulnerable groups that are difficult to reach and who themselves do not seek prenatal care when they are pregnant. As a result, they are often diagnosed with HIV during the later stages of pregnancy, when they are in labor, or even after the delivery. The sad consequence of this cycle is that more and more children are infected with the virus. According to the speakers, bringing the system up to an acceptable level will require the ministries of health to revise their regulations on PMTCT; develop a uniform, systemic approach to prenatal healthcare delivery; and establish close collaboration with international and national non-governmental organizations (NGOs). Additionally, speakers underscored the acute necessity of building a cadre of qualified healthcare professionals who will be able to assure high standards of prevention, follow-up, and support services, as well as to promote WHO protocols on PMTCT in the region.

## Ukraine's Adoption of WHO's Four-pronged Approach Cited as Successful Example of National Roll-out

Ukraine's experience with a multi-sectoral response to the prevention of HIV infection in infants was presented by Nadezhda Zhilka, deputy head of the Maternal

and Child Healthcare Department of the Ministry of Health of Ukraine, who explained that this successful model is one that can readily be adopted in CAR. Zhilka said Ukraine's strategy is based on WHO's four-pronged approach and links the efforts of different national and international agencies with the Ministry of Health taking the lead in educating and training maternal and child health specialists and primary care practitioners to provide PMTCT services at all levels of the healthcare delivery system, including women's clinics, obstetric hospitals, and pediatric clinics.

Over the course of the past three years, Zhilka explained, PMTCT has been introduced as a subject in the postgraduate education programs of medical academies throughout Ukraine and more than 900 OB/GYNs, neonatologists, and pediatricians have attended UNICEF-supported training seminars. Additionally, some 70 Ukrainian healthcare professionals participated in PMTCT courses offered at an AIHA-affiliated training facility in Odessa, the Southern Ukraine AIDS Education Center (SUAEC).

Using international and national experience, a number of handbooks and protocols on PMTCT and HIV/AIDS prevention were developed and approved by Ukraine's Ministry of Health, Zhilka said, explaining that these materials cover topics such as pre-and-post-test counseling, PMTCT in clinical settings, treatment and care of children with HIV/AIDS, and even recommendations for the integration of HIV-positive children into mainstream educational institutions. According to Zhilka, Ukraine has also improved its legislative framework for HIV/AIDS-related issues, including a state mandate that makes discrimination and stigmatization of people living with HIV/AIDS illegal and requires that they are given full access to healthcare services regardless of their social or economic status.

The comprehensive system of PMTCT in Ukraine is built on lessons learned from AIHA's highly successful Odessa PMTCT program, which was initiated in 2001 and in its first two years of operation resulted in a 75 percent decrease of vertical transmission at the Odessa Oblast Clinical Hospital (OOCH). In addition to preventing transmission of HIV from mothers to their babies, the Odessa project also facilitates broad, systemic change by helping to reorganize health service delivery, adapt evidence-based treatment protocols to limited-resource settings, develop training materials and curricula for healthcare professionals, and prepare a qualified cadre of professionals utilizing the resources of SUAEC, which is located at OOCH and was established by AIHA in 2003 to foster PMTCT scale-up efforts in Ukraine and other countries in the region. Nationwide implementation of WHO's four-pronged approach on PMTCT, in combination with the already established system of early registration for prenatal care and universal HIV screening of pregnant women, has resulted in a two-thirds decrease of risk of mother-to-child transmission in Ukraine, down from a pre-program rate of 30 percent to the current national rate of 10 percent.

### AIHA Spearheads Early PMTCT Efforts in Central Asia

In an effort to disseminate the success achieved in Ukraine, AIHA—with support from USAID and in close cooperation with WHO and UNICEF—initiated a regional effort to replicate the Odessa Model throughout CAR. The first program was established in Kazakhstan in 2003 because, with 4,696 registered cases of HIV/AIDS since 1987, this nation has one of the highest prevalence rates among all Central Asian countries. Plans were also made to establish similar programs in the

other Central Asian countries in 2005. As the first step of replication, PMTCT policymakers from Almaty, Karaganda, Pavlodar, and Temirtau—the cities with the highest HIV rates in Kazakhstan—visited Odessa in 2004 to observe the PMTCT model in action.

Commenting on the benefits he and his colleagues reaped from the Odessa experience, as well as various training courses conducted by AIHA, Nikolay Kuznetsov, head of the Karaganda Oblast AIDS Center, said that local healthcare professionals and policymakers were able to improve prenatal care for HIV-positive women by involving different agencies in the PMTCT service network and implementing WHO's PMTCT-related guidelines for the region. Karaganda's network consists of a regional AIDS Center, maternity hospitals, pediatric clinics, and several NGOs. It facilitates access to PMTCT services for women living with HIV/AIDS, especially those in vulnerable groups that are often stigmatized and discriminated against by healthcare providers—a phenomenon that greatly inhibits them from seeking prenatal care.



Specialists from Karaganda, Pavlodar, and Temirtau review the conference materials while getting ready for a group work. (Photo courtesy of Assel Terlikbayeva.)

Kuznetsov also described the important role of the Satellite Clinic opened at Temirtau Maternity Hospital to provide counseling services and social support to HIV-positive pregnant women. The clinic employs female counselors who themselves have given birth while being HIV-positive. Kuznetsov notes that because of their personal experience and knowledge of PMTCT strategies, these women can more effectively discuss key issues such as making informed choices about motherhood and the importance of early prenatal care. With this program in place, he explained, there has been a 50 percent increase in the number of HIV-

positive women who proceed with their pregnancies under the Clinic's care while the number of pregnancies among HIV-positive women has dropped by 1.2 percent. He also noted that a similar clinic is currently being developed at a Maternity Hospital in Karaganda.

In addition to offering PMTCT services and patient counseling, these hospitals are also considered "Centers of Practice Excellence" in accordance with the regional roll-out program and provide theoretical and hands-on training for professionals from other obstetrical and primary healthcare service institutions in the region.

According to Kuznetsov, another essential element of the replicated model is its case-based management and monitoring system, which was developed by OOCH staff and disseminated in the Karaganda Oblast AIDS Center and the maternity hospitals in Karaganda and Temirtau. This technology transcends institutional boundaries and provides information across a multi-institutional continuum of care, which is essential for the effective treatment and support of individual patients with HIV/AIDS, he explained.

Speaking about the efficiency of a similar model in Pavlodar, Sagit Imangazinov, head physician of the Oblast AIDS Center, said that within a year of the project's

start, local specialists observed a 13 percent decrease in unwanted pregnancies and a 30 percent decrease in deliveries among HIV-positive women.

## International Cooperation Is Critical for Future Prevention and Treatment Efforts

Ways of building partnerships with international health and donor organizations for implementation of the Strategic Framework for the Prevention of HIV infection in Infants in CAR were shared at a round-table discussion that took place on the second day of the conference. During this session, the participating international organizations were provided with an opportunity to openly discuss their strategies for addressing HIV/AIDS and how their projects relate to the prevention of HIV-infection in infants. Additionally, AIHA partners and representatives of other donor organizations discussed how they can better cooperate in the future to further support national PMTCT policy development and implementation of best practices in CAR.

Following the discussion, the participants worked in mixed groups to identify common challenges and future directions related to PMTCT and in country-specific groups to develop strategies and actions required at the national level to achieve their PMTCT goals based on both global experience and the results of individual pilot projects. In addition, they focused on the development of country-specific plans for implementation of the WHO Strategic Framework for the Prevention of HIV Infection in Infants and brainstormed the issue of what needs to be done to address the four main principles of the strategy.



Natalia Nizova, AIHA consultant for maternal/child health and HIV/AIDS works with Kazakh specialists on development of human capacity building plans to support country-specific interventions for PMTCT. (Photo courtesy of Assel Terlikbayeva.)

The issue of human capacity building to support country-specific plans was discussed during the final day of the event. To provide participants with effective tools and strategies for developing a qualified cadre of clinicians and allied health professionals to effectively implement PMTCT programs, Natalia Nizova, AIHA consultant for maternal/child health and HIV/AIDS, presented a comprehensive evidenced-based "PMTCT Generic Training Package" developed by WHO and CDC, which is currently being adapted by AIHA for use in Eurasian countries. US partners for Medical Education in CAR, Brian Bognar, associate dean, Undergraduate Medical Education at Health Sciences Center, University of South Florida and Patricia Charles, associate professor, University of Nevada School of Medicine, presented their work on the development of an undergraduate medical curriculum on HIV/AIDS for implementation in medical and nursing educational institutions in Central Asia.

Following these presentations, participants identified training needs in each country, including the number and types of specialists to be trained, the availability of educational materials, and the kind of support required from international agencies to better ensure an effective human capacity-building process. After that, they developed action plans for building a core group of PMTCT specialists in Kazakhstan, Kyrgyzstan, Tajikistan, and Uzbekistan, in part through the use of the PMTCT Generic Training Package. Participants also discussed strategies for

integrating a PMTCT component into undergraduate and graduate medical and nursing education in CAR.

As a result of the discussions held on the principal issues concerning implementation and development of strategies for the prevention of HIV-infection in infants in Central Asia, and given the realities of the developing HIV/AIDS epidemic in the region, conference participants formulated a summary of problems and primary needs that they will present to the legislative and executive authorities of their respective countries.

Summing up his experience at the event, Bekbay Khairulin, chief pediatrician at the Kazakh Ministry of Health, underscored that its timing was particularly appropriate because his country is now home to 139 children born to HIV-positive mothers. Twelve of them have already been diagnosed with HIV, while the status of 54 more has not yet been identified. "Exposure to international experience and the development of national programs on PMTCT in CAR will help us significantly decrease and control the further spread of HIV/AIDS in infants. Moreover, it will give us a chance to help HIV-positive women deliver healthy babies and thus realize their right to motherhood."



## AIHA Partner Recognized for Her Contributions to Professional Nursing in Armenia

Long-time AIHA partner and consultant Linda Aiken, director of the University of Pennsylvania's Center for Health Outcomes and Policy Research, was recently honored by the Eastern Diocese of the Armenian Church of America and the Fund for Armenian Relief for her contributions to the development of professional nursing in Armenia.

During a ceremony at the Diocesan Center in New York City on May 26, Archbishop Khajag Barsamian presented Aiken—who spearheaded AIHA's Nursing Quality Improvement Initiative (NQII) in Armenia and Russia—with an award recognizing her efforts to introduce Magnet Nursing Standards at two AIHA partnership



Archbishop Khajag Barsamian gives Linda Aiken an award for her contributions to nursing excellence in Armenia. (Photo courtesy of Linda Aiken.)

hospitals in Yerevan: Erebouni Medical Center and St. Grigor Lusavorich Medical Center. Among the numerous guests who attended the celebration were AIHA Executive Director James P. Smith; Jeanne Floyd, executive director of the American Nurses Credentialing Center, which manages the Magnet Recognition Program; and representatives from UCLA Medical Center and North Shore University Hospital, the two US hospitals that partnered with the Armenian institutions on the project. (For more information on the NQII, please see: "Four AIHA Partnerships Receive International Award for Excellence in Nursing").



**Lusine Poghosyan and Linda Aiken.** (Photo courtesy of Linda Aiken.)

Attending the ceremony was Lusine Poghosyan, a member of the first class to graduate from Erebouni Nursing School's Baccalaurate program, which was established through the efforts of the Yerevan/Los Angeles partnership with support from AIHA. Having worked with Poghosyan during the course of the NQII project, Aiken introduced the Armenian nurse to participants at the ceremony, proudly explaining that after graduation she continued on her path to professional development by obtaining a Masters in Public Health from the American University of Armenia, and now is getting her Ph.D. in nursing from the University of

Pennsylvania. "When she returns to Armenia in several years, she will represent a new generation of Armenian nursing faculty trained at high international standards," Aiken said noting that Poghosyan will be the first Armenian nurse to receive such a high level of education in nursing.

Speaking about Aiken's achievements, guests underscored the tremendous role she played in pioneering the implementation of Western standards of excellence in low-resource countries where nursing has long been underdeveloped. Due to her constant striving and willingness to take risks, AIHA's NQII resulted in increased professional autonomy for nurses at participating institutions in Armenia and Russia, as well as significantly higher levels of job satisfaction. In addition, the substantial expansion of nurses' roles and responsibilities—coupled with the implementation of 14 Magnet quality standards—allowed the participating hospitals to create an institutional infrastructure that supports nursing and fosters better professional relationships between physicians and nurses, thereby greatly reducing rates of nosocomial infections and improving both quality of care and patient satisfaction.

Sharing her thoughts on the project with her colleagues at the ceremony, Aiken said, "The Nursing Quality Improvement Initiative in Armenia and Russia demonstrated that hospital quality of care can be fundamentally improved through investment in professional nursing." Explaining further, she continued, "We created a practice environment for nurses that not only improved quality of care, but will also help these countries retain well qualified nurses at a time when international recruitment of healthcare professionals by wealthy nations is escalating. We would like to see other hospital quality improvement initiatives



American partners from UCLA: Salpy Akaragian, director of the International Nursing Center, and Heidi Crooks, vice president of nursing, congratulate Aiken on her award. (Photo courtesy of Linda Aiken.)

replicate our success by strengthening professional nursing."

## **Regional News**

# HIV/AIDS Vaccine Development: A Matter of Global Partnership in the Fight against the Virus

Every day 14,000 people worldwide become infected with HIV/AIDS. More than 20 million men, women, and children have already lost their lives to AIDS and some 40 million more are currently living with this virus. Although antiretroviral drugs (ARVs) have been developed and progress has been made in making them available in the countries with burgeoning epidemics, these medications are not an effective deterrent against new infections. To prevent the HIV from spreading, a vaccine that can trigger the body's immune system to create strong defenses that stop infection if a person is later exposed to the virus.

"The road to an AIDS vaccine: where we are, and where we need to go" was the theme of a meeting held May 18 at the Global Health Council in Washington, DC. The event brought together representatives of different American and international organizations working in the sphere of HIV/AIDS and was designed to mark the Eighth Annual HIV Vaccine Awareness Day, as well as to provide a forum for the discussion of the latest advances in HIV vaccine development.

Key speakers were Mitchell Warren, executive director of the AIDS Vaccine Advocacy Coalition (AVAC); Peter Minyike, acting co-director of the South African AIDS Vaccine Initiative (SAAVI); and Patricia Fast, director of medical affairs at the International AIDS Vaccine Initiative, which is the world's largest organization focused solely on the development of an AIDS vaccine.

According to Fast, about 650 million US dollars are spent annually on the research and development of an AIDS vaccine, although more financing is needed to fully address fundamental underlying scientific challenges, as well as vaccine development and testing.

"HIV vaccine is not only a scientific issue, it is also an issue of finding candidates, preparing them for trials, and educating specialists and community members about the research process. This takes additional time and huge financial and human resources," Fast said.

Up to date, IAVI's scientific program has developed a number of vaccine candidates from the concept stage to human clinical trials and continues to evaluate other candidates in preclinical laboratory studies to determine if they should be tested in human trials. These candidates elicit broadly neutralizing antibodies, which may be a critical part of an effective vaccine. According to Fast, the issue of viral diversity is the most difficult subject researchers face on their way to vaccine development, necessitating the exploration of a number of different strategies in the attempt to effectively address this question.

Although 30 vaccines have already been tested in clinical trials sponsored by IAVI in Africa, Europe, India, and the United States, none of them has demonstrated efficacy so far. While the research continues, Fast noted the importance of

implementing scientific programs and ensuring the development of safe, effective, and accessible HIV vaccines—particularly in Africa where HIV/AIDS is now the number one killer. To this end, IAVI and SAAVI are working together to build trial sites, including state-of-the-art laboratories in four African countries that have been hit hardest by the epidemic: Kenya, Rwanda, Uganda, and Zambia.

Discussing the implementation of research projects in these countries, Fast underscored the importance of addressing behavioral issues and HIV/AIDS education in conjunction with vaccine development. "There are many places where people do not know how HIV/AIDS is transmitted and where there are challenges in implementation of pre-and -post test counseling because of the stigma attached to AIDS," she said, stressing that it is also critical to promote awareness among political, financial, and scientific leaders about the urgent need for an AIDS vaccine and encourage them to become advocates for improved programs.

Saying this, Fast appealed to the representatives of non-governmental organizations and international donors who develop HIV/AIDS-related programs in diverse parts of the world in attendance at the meeting, asking them to promote HIV/AIDS awareness and education among the general population and political leaders. According to her, global partnership efforts against HIV/AIDS will diminish the risk on new infections and help accelerate the process of vaccine research and development, as well as the approval, production, and use of future vaccines in those countries where the need it is greatest.

Supporting her call to action, AVAC Executive Director Mitchell Warren said that every organization involved in the HIV/AIDS response has a role to play. "We do not know when the vaccine will be found, but what you all can do to advance this time is to think how the vaccine can be integrated into your programs. Participate in trials, be involved in your community, integrate these issues into your work, and don't leave them to the scientists. We can't do it without them, but we can't do it with them only!"

# New Healthcare Project Partners Ukrainian and Foreign Hospitals

A new charitable project of the Ukraine-3000 Foundation named "From Hospital to Hospital" was launched by Kateryna Yuschenko, first lady of Ukraine and head of the Foundation's Supervisory Panel, during an event May 19 at the Bogdan and Varvara Khanenko Museum of Arts in Kiev. This five-year project is aimed at finding partners from Western Europe, the United States, and other parts of the world for 25 Ukrainian hospitals, according to a report published by *Ukrinform*.

The ceremony was attended by diplomatic representatives of several European nations, Canada, Japan, and the United States. His Royal Highness Prince Michael of Kent, Foreign Minister of Ukraine Borys Tarasuik, and Ukrainian Health Minister Mykola Polischuk also attended at the request of Yuschenko, who asked for their help in improving Ukraine's healthcare system.

Explaining the need for such assistance, Yuschenko emphasized that the state of healthcare in Ukraine is far below European standards even while one out of three Ukrainian citizens experience health problems that require qualified medical care,

says Correspondent.

"I call on you to assist us in finding medical institutions ready for partners in your countries and, if possible, to make contributions to this program's budget for the next five years. A healthy and flourishing Ukraine is in the world community's interest," said the First Lady.

If you want to know more about this project, please, send your questions to: info@ukraine3000.org.ua, or call: 38-044-467-67-88.

## Workshops, Conferences, Opportunities and Grants

#### 20th European Congress of Pathology

The biannual conference of the European Society of Pathology will gather healthcare specialists from throughout the world to exchange new information and share recent advances on a variety of different health pathology topics. The congress will take place in Paris, France, September 3-8, 2005. For more information about the event, please go to: <a href="https://www.pathology-congress.com/index.html">www.pathology-congress.com/index.html</a>

#### Congress of European Society of Cardiology - 2005

More than 25,000 attendees will gather in Stockholm, Sweden, September 3-7, 2005, to attend this major event in the world of cardiology. Sponsored by the European Society of Cardiology, the congress will provide attendees with both the best of science and the best of education in all areas of cardiovascular medicine. This year, however, a special emphasis will be placed on cardiovascular health in women, a topic attracting more and more attention every year. For additional information, please, visit:

www.escardio.org/congresses/esc\_congress\_2005/

#### 13th World Congress on Psychiatry

The theme of this congress, "5,000 years of Science and Care: Building the Future of Psychiatry," reflects both a mixture of old, but effective practices, and new achievements in the sphere of psychiatry, as well as charts a course for future progress in the field. The congress will discuss state of the art advances in neuroscience against the backdrop of the many complexities facing the psychiatric profession today. The eveny will be held in Cairo, Egypt, September 10-15, 2005. For more information, go to: <a href="https://www.wpa-cairo2005.com/xiii">www.wpa-cairo2005.com/xiii</a> welc.html

#### 12th Annual Meeting of the International Herpes Management Forum

One of the primary aims of the IHMF is to develop international recommendations and guidelines on the management of viral herpes infections. The annual meeting will provide an opportunity for these recommendations to be formulated and debated on an international level. The conference will be held in Lisbon, Portugal, October 28-30, 2005. For details, please visit:

www.ihmf.org/IHMFActivities/12thAnnualMeeting.asp

### **Features**

# Battling the Lion: Vanquishing Fear and Choosing Life After Being Diagnosed with HIV/AIDS

We stood by the front entrance of a Kiev hotel and talked about life and death. A ventilation unit roared somewhere nearby, blasting hot air right in our faces. Then suddenly it shut down and the icy February air quickly crept in through the crystal cold windowpanes stinging us with frigid drafts. We both started to shiver. Paying no attention, he continued to speak and I to listen. I would have been ashamed to suggest that we find another place to talk. It would have sounded pathetic because at that moment he was telling me about how to be strong.

"If you meet a lion face-to-face, you can run away and feel your terror grow by the second as you anticipate that he will overtake you and tear you to pieces with his teeth. Giving in to that fear, however, means death. But if you stand and fearlessly look him in the eye, the lion will not touch you. You may not ever free yourself from him and become entirely safe but, by killing the fear in yourself, you can hold death at bay," he said simply and with confidence. He was talking about how he lives with HIV/AIDS.

Carlos Cordero is a handsome Puerto Rican who came to the United States at the age of 17 and realized the American Dream by becoming a model for the international fashion powerhouses of Armani and Ralph Lauren, as well as the face of Pepsi. He is also one of the few lucky people to spin the wheel of



**Carlos Cordero** (Photo: Vira Illiash.)

fortune and become a real-life lottery winner. But Cordero gave up that glittering world of tinseled beauty and became a healer of hearts for outcasts who have no hope of salvation. He still travels the world and puts himself on display as he did during the years he spent on the runway posing for the cameras, but now the ethereal fantasy of beauty has faded. What is important to him now is dispelling the myth of death that surrounds AIDS. What is important is demonstrating the miracles created by antiretroviral therapy. What is important is inspiring people by speaking openly about his life and his experiences. And what is very, very important is not to be afraid of His Majesty AIDS, who is rivaled in power only by his constant companion-omnipresent and boundless fear.

Cordero's story is commonplace, yet unique. The path that led him to HIV is a familiar one to many people living with this virus, but the road he chose since being diagnosed is unusual because it is full of life and light.

HIV came into Cordero's life through a stormy, short love affair that left nothing more than the virus in its wake. He found out he was infected in October 1992, a few months after breaking up with his lover. "That was one of the most sobering moments of my life. I went out onto the street and didn't know where to go. My

thoughts rushed around, trying to break through the fear and despair. The only thing I was thinking about at that moment was whom I would tell and whom I wouldn't tell, but suddenly I understood that hiding it was no way out. I decided to tell all my friends and acquaintances without exception and to stick with the ones who would really support me." As he said this, he looked me straight in the eye and I understood that he was speaking in the broadest sense. He was talking about genuine relationships of the sort many of us seek in life and about openness, which is one of the ways to find them.

Many people turned away, he admitted. Most of them, in fact. But the ones who remained were those whose support and caring for him knew no bounds and needed no justification. It was their love and succor that paved the way for his decision to close the door on fear and embark on the pathway to life.

"I decided to follow through no matter what the consequences. It was November, shortly before Thanksgiving. I decided to go and visit my family in Puerto Rico and tell them that I was sick. I hadn't seen them in 14 years. My friends tried to convince me not to go, but I don't regret it in the least." His words sank into my mind and I thought about how we often keep quiet about things that bother us only because we are afraid of the moment of truth. But how does a fleeting moment of discomfiture or even shock compare with the constant pain and embarrassment brought on by stigmatization and fear? He read my thoughts and added: "If my grandmother had had a stroke, it would not have been because I am sick, but because she has high blood pressure." That sounded harsh, but I realized he was right. Silence is an invisible shell of lies that cannot last forever. Sooner or later it will be penetrated by a cry of despair and reproach and it doesn't matter whose cry it is—the person who was keeping silent or the one that silence was supposed to be protecting. That is when things get really painful.

Cordero went on with his story, his words pulling my thoughts back to the present. "All the members of my large family from my grandmothers to my little nieces and nephews gathered for Thanksgiving. I told them that I wanted to know how they relate to me here and now not when I'm dying and see their faces distorted with pity. My being so direct and firm about this gave them confidence that I would not give up and that they should follow my example. I had always had fairly difficult relations with my family, but at that moment the invisible wall that had divided us all those years came crashing down and we all became much closer."

Four years later, Cordero was already very sick. At that time, there were no effective drugs to treat AIDS and death was the logical outcome of the disease. "In May of 1996, I was sitting in a wheelchair certain that I would not last past August. I had a whole array of diseases. I couldn't walk and I had to have food delivered to my apartment. Then suddenly I got a call from the Olympic Committee in Atlanta offering me a job. I had applied a year earlier, when I was still on my feet. I had always dreamed of working at an Olympics." Because of his language skills-he speaks English, French, German, and Danish in addition to his native Spanish—the job offer was for the position of translation manager for water sports. "They were talking to me on the phone and I was looking at myself in the mirror and thinking with horror that my lifelong dream would not come true. But then I asked when the Olympics would begin and they said in July. I thought: there's still time and I took the job without knowing why I did it." He smiled, remembering the moment and I was surprised he looked so happy. Hearing what happened next, though, I

understood why he did.

"After I hung up, I felt a surge of energy like I hadn't experienced in a long time. I started doing physical exercise, revised my diet, and changed my attitude toward medicines, telling myself that they were vitamins that would help me get back on my feet. Before that, I had seen them as poison, which sooner or later would kill me. I forced myself to believe that even if my life was going to end in August I would be living out my dream in July." It was clear from his tone that, for him, the word "living" had only one meaning. At such moments you realize the weight that words can have, how they perform differently in the complex arena of language when they come from the lips of one person or the next, and how their value is tempered by each individual situation. For Cordero, "living" meant to drink life in big gulps, tasting it like a fine wine, distinguishing one subtle element of its flavor from the next, and—most importantly—not to be alone, but to maintain contact with people and to be inspired from within.



During the ART workshop in Kiev Cordero shares his philosophy and experience in fightig the virus with the social workers from Ukrainian AIDS Centers. (Photo: Vira Illiash.)

I glanced around to see what was going on behind me, instinctively searching for signs of life from other people who went about their business outside the of our conversation. In the foyer, a handful of people were sitting on sofas in frozen poses while a TV blared over the bar. Behind me, a guard stood gloomily inspecting his walkietalkie. I turned back and saw Cordero's pensive face. He continued his story: "After the Olympics, I went back to bed as if the spark inside me had died out. Lying there, I thought about what it was that had gotten me out of bed the month before. And suddenly I understood that it had not been the medicines or the healthy eating, but rather my desire to see the next day. I needed to have a goal to work for. I had to see something in front of me, something that would make me want to get up in the morning. That was the day I

realized that this was the prescription for bringing myself back to life."

As I listened, the thought suddenly occurred to me that there was a pure and simple truth in his words, some idea that had always existed in the back of my mind, but never found its way to the forefront where I could give it my full attention. While I was thinking about why this might be, he said: "During all my years in modeling I was the incarnation of many people's fantasies. They liked how I looked and how I dressed. They judged me from the outside, which showed very little of who I really was. But I always wanted people to like me for myself, for who I am on the inside as an individual. I always wanted to do something for people, for their souls, and their lives." He said this with such passion that for a moment I envied him his illness realizing that it was the dreaded virus that had given him back such a crystalline understanding of authentic values as well as the opportunity to turn his life around.

Gradually, by trial and error Cordero began to understand that he could no longer sit on his hands waiting to die. As his disease developed, it pushed and prodded him along a different path, a path toward life. "At that time, I was diagnosed with

cytomegalovirus as a result of my immune deficiency. This caused a premature development of retinitis—a disease that blinds a person in a number of months. The treatment that was recommended was the installation of a special port in my heart to deliver a medicine directly into my circulatory system that would prevent the development of this disease. This was a permanent treatment and I told my doctor I wasn't ready for it. He couldn't believe his ears, but I signed a written release and walked out of his office."

As soon as Cordero got home, he called a travel agency and bought a ticket for Paris. "Before losing my sight I wanted to imprint something very beautiful in my memory. I spent one week in Paris and tried not to think about anything other than the delight of what I was seeing. When I got back to New York, I took a flight home to Puerto Rico because I wanted to say good-bye to the scenes of my childhood, the ocean, and the sky. I spent a whole month on the beach. I swam and dived trying to memorize the beauty of the sea bottom and to say farewell forever to the fish and the crabs. When I returned to New York, I went straight to my ophthalmologist who examined my pupils, raised his brows in surprise, and said with some puzzlement, 'Carlos, I don't understand anything here.... Where did it go?' At that moment I felt that I had beaten the lion for a second time just by refusing to be afraid or to run away. I simply told the lion, 'You'll just have to wait because I have more important things to do.'"

We both laughed and I suddenly realized that I wasn't cold any more.

### Seeking Treatment to Live Means Learning to Live with the Treatment

Cordero was one of the patients who took part in the testing of triple combination antiretroviral therapy in 1996. Before then only one or two regimens had been in use—the so-called mono- and -double therapy regimens. The advantage of triple therapy is that all three of the drugs the patient takes act in a variety of ways, suppressing the virus. This allows the immune system to be restored. The patient has to take the drugs all at the same time in order to keep the viral load to a minimum. So far, this remains the only treatment science has come up with. The medications do not cure AIDS, but they can enable people infected with HIV to lead a normal life.

"I had many doubts about whether or not to take these drugs, but I chose to live and without them it would have been impossible to prolong my life." I know that many people living with HIV are afraid to begin taking drugs because they dread the side effects. That frightened me, too, because I had seen people who were on mono-therapy and they didn't look rightblue fingernails, blue lips, and hair falling out. But that was back in 1992. Science has advanced since then, and I hope I look healthier than the patients I just mentioned," he smiled, somewhat guizzically. I nodded in response, letting him know that he looked great. And so he



Cordero visits intravenous drug users at the Kiev AIDS Center to talk about the positive effect of ART and to encourage them quit drugs and choose life. (Photo: Vira Illiash.)

did, with a muscular, well-built body clothed in a tight-fitting wool sweater and elegant jeans. He had a healthy color to his slightly dark complexion and a very

calm, confident look in his nut-brown eyes. The thought crossed my mind that only models look like that.

Suddenly he pulled his passport out of his pocket, opened it to the picture page, and offered it to me. It looked to be the passport of a rather portly, 50-something man. I looked up at him in perplexity, not knowing what to think. Cordero laughed and flicked his finger first on the picture and then against his forehead. "That's me," he said, and, waving the passport as he put it away, added, "That's me with lipodystrophy—one of the side effects of antiretroviral therapy that I experienced when I first started taking the medications. I also went through many other unpleasant adventures, including shingles, a condition where you're always on the brink of shock from pain." For a second, his head sank back, but then he straightened abruptly as if he had cast off some weight and went on, "But all those unpleasant experiences had a positive side. They meant that the drugs were working. AIDS caused me to come down with several forms of cancer, but the antiretroviral drugs saved me again. One of the medicines in the triple combination regimen I take acts especially on atypical cells, blocking their development. So it comes down to what prospects you can see beyond the difficulties."

Obviously my face betrayed a certain bewilderment that he had seen before, because he nodded with understanding and asked: "Do you have roller-coasters in Ukraine, what they call 'Russian hills'?"

"You mean the amusement-park ride?" I replied. "We have them, but we call them 'American hills'."

"Everything depends on how you look at it, he said, and we laughed at his joke, but then he continued the thought. "So, there are two ways to ride them. The first is to grab the rail and try to hold on with all your might for the whole ride. The second approach is to raise your arms in the air and just feel all the twists and turns of the track. Doing it the first way, you can get a hernia. The other way, you just delight in experiencing those moments. But the ride is the same. It has all the same sharp turns and headfirst downward drops. Life with AIDS is the same. The disease is there, with its complications and unpleasant sensations, but a person's quality of life depends on him alone. If he takes ART, he can control it. He can live! And all of these trials just help you understand how to act in order to deal with them."

Suddenly I thought of a superhuman. Maybe the person in front of me was a modern Zarathustra, who had gone through serious testing, overcome human weaknesses, and achieved spiritual freedom. I don't know about that, but his attitude toward his disease was clearly something unrealistic for ordinary human beings. Not only because he had been able to survive all of this, but also because he knew exactly how and did it.

Cordero had explicitly decided to raise his arms in the air and do everything he could to "enjoy" a ride. For this purpose he has created his own philosophy of life with AIDS, which from the outside appears quite simple. He adheres very strictly to his drug regimen, does physical exercises every day, eats vitamin-rich food, and does what he likes. "When you're doing something that brings you pleasure, you get a bigger dose of positive energy—healing energy. I finally found something that gets me up in the morning, and that is my work." And, there is a story to that part

of this unique man's life as well.

"When I was already seriously ill, I won a fairly large amount of money in the lottery. I wasn't in the mood to have a good time just then, but nevertheless I decided to fulfill my dream and see the world. To tell you the truth, I'm only now beginning to understand how limited my world was at that time," he shrugged. "Once when I was in Morocco, I suddenly felt as if I were doing something wrong. I felt as if all the good times and night life were laying waste to my soul when what I really wanted was to find something that brought me fulfillment. It was then that I decided to go alone into the desert that divides the southern part of the country from Mauritania and to think about what was tormenting me. I was completely alone in the midst of absolute poverty and destitution and suddenly I realized that I wanted to help these people."

The next stop on Cordero's tour was Berlin. Arriving there he went straight to the regional office of Doctors Without Borders, which runs various medical programs in more than 80 countries worldwide. By that time, he already had a fair amount of experience with HIV/AIDS-associated opportunistic infections and he knew the principles of how antiretroviral drugs work and their side effects as well as any doctor did. What's more, he had his precious philosophy of life in his pocket, so he offered his services. "They asked me what my field of medical specialization was. I replied that I was a patient who could discuss first-hand the nature and the symptoms of this disease and how to live with it. When they told me that they didn't have such a program, I asked them to create one."

From that fateful conversation in Berlin, a new journey began. Congo, Ethiopia, Uganda, Zambia—Cordero's world started to expand as he traveled through these sub-Saharan African countries that have been wracked by the epidemic. This part of Africa has just more than 10 percent of the world's population, but is home to more than 60 percent of all people living with HIV. Eleven million people there have died of AIDS, a many of them women and children.

Several years ago, many developing countries that were hardest hit by the HIV/AIDS epidemic and struggling against failing economies to provide treatment to their citizens received assistance from international donors for the purchase of antiretroviral drugs. The availability of these medicines brought with it the need for qualified specialists with experience in treating and caring for people living with HIV. Cordero became one of the few missionaries to offer his services to the medical professionals in those countries and bring light into the life of many families exhausted by the deaths of those near and dear to them, while at the same time coping with the fear of losing their own lives. "I go to places where AIDS is taking away more lives than all other diseases combined, to places where people had never known that it was possible to live with this virus and had never heard about treatment options. For them, AIDS means only one thing: death. I meet these people and tell them about the opportunities antiretroviral therapy offers, about how if you take it you can come back to life, go to work, give birth to healthy children, and plan for life in the future instead of your funeral. I teach them how to take the drugs properly and how to combat complications and they tell me their stories," he smiled, looking through me to some other place, evidently remembering each person who touched his life just as surely as he had touched theirs. His eyes began to moisten, filling with the sparkle of poignant tears and I felt grateful that the person standing in front of me was so extraordinarily

#### authentic.

During that pause, I recalled the film he had shown me the day before our conversation. Cordero made the short movie in Uganda where HIV is transmitted chiefly by sexual contact. It showed young girls with shaved heads, dressed like boys. According to him, this disguise was to protect them from being raped on the street. The gaunt faces of men stared into the camera and brightly dressed women shot timid smiles in his direction as he filmed them going about their day-to-day activities. Many of these women never experience sexual pleasure because they undergo female circumcision immediately after birth. As a result of this painful procedure and age-old cultural practice, sexual intercourse brings them more pain and much bleeding, which indicates successful completion of the sex act. Because of such practices, HIV is spreading in Uganda with unprecedented speed. The film showed the abject poverty of the slums where these people live before finally focusing on a modest health station constructed of bamboo. This is where the local inhabitants had gathered to listen to Cordero's story. Many of them were smiling and the men somewhat awkwardly embraced their women. I remembered Cordero commenting to me at that point that he asks them to do that more often because such displays of affection are not generally accepted in Uganda. He also told me that people there rarely kiss.

Cordero has been working in these countries for three years now and he and his colleagues have achieved good results in patient adherence to ART, which is the most important factor in the therapy's efficacy. If a person takes the drugs improperly, his body can develop resistance to them and they become impotent against the virus. To prevent the development of a drug-resistant virus, the patient must take the medicines at the exact same time every day with very little deviation from the schedule. Adherence needs to be at least 95 percent but, to achieve this, the patient needs to know everything about his disease, the drugs, and himself. Cordero is convinced that those three basic principles should define the rules that govern the lives of people taking these drugs. "We were able to achieve 100 percent adherence to therapy in Ethiopia and 97 percent in other countries. But, unfortunately, nobody was interested in our results. So I decided that I myself should take part in various NGO projects so I could help people living with HIV change their quality of life for the better."

It was this desire that brought him to Kiev at the end of the fierce Ukrainian winter. By that time, revolutionary passions had cooled in Ukraine and time—like the Dneeper River—seemed frozen by the silent expectation of approaching changes. Everybody was waiting together, but each dreamed about something deeply personal. The 400,000 Ukrainians living with HIV were certainly dreaming that some attention would be paid to their needs. AIDS specialists were dreaming about the same thing.



Carlos Cordero with his international collegues who served as trainers during the ART course in Kiev: Alexander Telnov, project physician at Medecins sans Frontieres' office in Odessa, Svetlana Antonyak, head of the AIDS Unit at the Infectious Diseases Hospital associated with the L.V. Gromashevsky **Epidemiology and Infectious** Diseases Research Institute in Kiev, and Christoph Weber, infectionist at the AIDS Clinic in Berlin. (Photo: Vira Illiash.)

Ukraine had finally purchased a large shipment of antiretroviral drugs in August 2004 thanks to a grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria. Before that acquisition, only a few hundred people in the entire country had received treatment, though thousands needed it. With the availability of the drugs, however, came many new problems particularly those stemming from medical specialists' lack of knowledge about treatment, care, and support of HIV-positive people. But this was not a problem for clinicians alone. Like the virus itself, the process of treating HIV/AIDS is complex and multifaceted, which necessitates a team approach to care. In countries with greater experience treating people living with HIV/AIDS, the care team includes a doctor, nurse, and social worker, along with additional specialists and allied support as needed. Such a system does not yet exist in Ukraine, although medical professionals and representatives from public HIV-service organizations are trying to develop one based on foreign experience in collaboration with international organizations.

The AIHA is one of the international organizations that is working with Ukrainian specialists to teach them the basics of ART. For this purpose, in March 2004, AIHA, in close cooperation with WHO's Regional Office for Europe and Deutsche Gese Ilschaft fur Technische Zusammenarbeit (GTZ), opened the Regional

Knowledge Hub for the Care and Treatment of HIV/AIDS in Eurasia. The Hub brings in specialists with extensive clinical and teaching experience from Europe and America to share their knowledge and expertise with local caregivers. Cordero was asked to take part in one of its workshops. He worked with individuals from public HIV-service organizations who provide psychological and social support to AIDS Center patients in six of Ukraine's largest regions. Most of these patients are HIV-positive. Before medicines became available, each of these individuals was fighting for his life while walking a virtual tightrope between the devastating stigma and discrimination commonly doled out to people living with disease by society at large and the government's indifference to their plight. It was a gloomy half-life with very little hope for treatment let alone a future, nevertheless they stood up for their rights, creating the public organizations that are now the only source of social and legal support for HIV-infected Ukrainians.

Attending the lectures Cordero gave these people, I saw how his words—and especially his energy—has the power to change them. I watched their pessimism evaporate and their eyes catch fire, kindled by his spirit. And, I saw the lion depart, growling in annoyance as it was vanquished by their renewed hope and faith in the future.

"Adherence to therapy is impossible without social and psychological support. If the government cannot provide this help, keep doing it yourselves. Don't wait for somebody to help you!" he said heatedly, taking leave of his Ukrainian colleagues.

"Your patients' needs do not depend on the government's financial capabilities. You have to give them knowledge and teach them to observe the three basic principles: adherence, a healthy lifestyle, and positive thinking. Before there was any therapy, we used to be called people with HIV. Now we have become people living with HIV. The significance of that one word is life—and that's a very big difference."

Those words reverberated in my head as I left the hotel. There was a bone-piercing February frost outside and the cold winter sky, illuminated by the city lights, hung low overhead. It seemed as if I had just been somewhere on another planet where the sun shines brightly and people know how to value what most of us on Earth do not.

"And what is it, really, that keeps us from living?" the words of Remarque's character from his "Three Comaraderies" came to my mind: "Nothing at all!" With genuine amazement, I thought to myself, "Nothing... you just have to be able to do it." With that discovery, I went back to my ordinary life wondering how there was nothing more to add to this thought of mine.

—Unless otherwise noted, all stories in this issue are written by AIHA Staff Writer Vira Illiash who is based in Kiev, Ukraine.