Regional Session on Europe and Central Asia
Kaiser Family Foundation
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[START RECORDING]

MICHEL KAZATCHKINE: [Speaks in Foreign Language].

NATALIYA LEONCHUK: [Speaks in Foreign Language].

ANNA SHAKARISHVIL: [Speaks in Foreign Language].

MALE SPEAKER: [Speaking in foreign language]. It is now my pleasure to introduce Jeff Lazarus, we're privileged to now have Jeff with us at the Global Fund. I understand he will deliver his talk of behalf of WHO and in his former capacity as Advocacy and Community Relations Advisor on communicable diseases in WHO, Copenhagen. Jeff. I strongly encourage the speakers to keep to their time, otherwise we will not make it to the session and we'll have not time for questions.

I would also, Jeff encourage you to really focus on Eastern Europe, looking at how many people were used headphones to listen to Anna, I think this is really the key interest here in the audience here today, thank you.

JEFFREY LAZARUS: Okay, thank you Michel and thank you very much to the session organizers and the IIS for the opportunity to present today, I'm truly honored.

And thank you to all who have contributed to this presentation, in one way or another more than 50 individuals have contributed. It is their work I will present on behalf of the HIV in Europe Initiative and not actually on behalf of WHO. WHO is a part of this initiative, which I joined in 2007 while

working there, and I'm now an observer on the steering committee, representing the Global Fund.

And let me also thank my former colleagues at WHO for loaning me the treatment scale up slide I will show, but also to acknowledge the amazing work that has been coming out of that office, not just targeted at Europe. The 500 pages of treatment and care protocols, which we all use, the harm reduction technical tools and advocacy and the current testing guidance for Europe, just to highlight a few things.

The HIV initiative in Europe is unique, not least in its constituency. Let me ask all of you to think about how you would categorize yourself? Are you a clinician, nurse, or other health care provider? Do you work in an NGO? Are you based at an academic institution? How do you collaborate with other disciplines? The initiative brings together representatives of all three groups. Their regular steering committees, five ongoing projects, and in three years two major conferences have been held, in Brussels and Stockholm.

In my presentation I will address the problem of late diagnosis in Europe and Central Asia, ART coverage among people living with HIV and the HIV in Europe Initiative itself, including barriers to testing and research in action to overcome these barriers.

As we heard there are an estimated 2.3 million people living with HIV in the WHO European region and around half of

them remain undiagnosed, a far better situation than in Sub-Saharan Africa, but not nearly good enough. Why? Because individuals who are unaware of their HIV status cannot benefit from treatment.

Undiagnosed HIV delays risk-reduction counseling and other prevention opportunities, prolongs the initiation of antiretroviral therapy, which we all know reduces viral load, and thus transmission. It is associated with increased time to mortality as compared with people living with HIV on ART and it increases medical costs.

The ECDC wrote in their special report on the Dublin Declaration released this year, that the issue in the European region is not really one of access to treatment for those who have been diagnosed as HIV positive and have been shown to need treatment.

Rather the issue relates to late diagnosis, i.e. those who need treatment but have not yet been diagnosed. While access to treatment is an issue for some who have been diagnosed, their research has shown that the main problem in treating those in need lies with the large group of undiagnosed individuals. Who are they and where do they live?

We heard about some of these groups from Annie and sometimes it's too easy to forget that we are asking people to get tested for HIV regularly in environments where people living with HIV still suffer a great deal of abuse and

discrimination and where they may even be criminalized because they use drugs, are gay or are sex workers.

Here, with regard to the number of people living with HIV who are unaware of their status we can see that there is great variance among countries in-between the west and east of this vast European region. In Ukraine for example only 100,000 of estimated 340,000 people living with HIV are aware of their infection. In Belarus there is a higher proportion almost half of the 17,000 people living with HIV are aware of their status.

Limited access to HIV testing and counseling will and is having an impact on early treatment and the prevention of further transmission of HIV. And this is especially true among most at-risk populations.

Let us recall what Anya Sarang in her plenary speech on Monday, that in societies where drug users are so discriminated against, and often imprisoned what is the incentive to engage with the health system to get tested for HIV.

We've heard over and over at this conference that treatment need is outpacing treatment scale up; this is also the case in Eastern Europe. However, the latest data from WHO Europe shows that while less than 250,000 people in the region were on treatment in the beginning of 2003, by the end of 2008 the number doubled. And the figure increased by almost five fold in Eastern Europe where some countries with no one on treatment or very few on treatment, introduced HAART.

It is a slow and at times painful process to witness, but there have been improvements. These must be maintained and scaled up. I look forward to the new treatment data to be released this autumn, including who is getting treated and I'm hopeful that it will show a continued, reasonably sharp, upward curve.

Some further data is available with regards to people who inject drugs on treatment, both at this conference, in several posters, in presentations, but also in the Mather's and Colleagues and Lancet 2010 ART Coverage Among IDUs article. I know you can't read this but suffice it to say there's inequitable treatment access for people who inject drugs.

Let's take Ukraine where more than 1 per 100 people are living with HIV as we heard, as an example and thanks for Annie at UNAIDS for this slide. It shows the inequity in Ukraine, a big country and a country known for its progress in expanding ART and harm reduction programs.

Yet we see serious challenges, some 40-percent of reported cases through unsafe injecting drug use. The dark blue on the bar on the left shows the percentage of people who inject drugs and who are on ART. The middle bar shows the percentage of all reported HIV cases.

Comparing the two, shows that people who inject drugs are greatly underrepresented among those getting treated for HIV. In Eastern Europe and Central Asia, among 100 people who

inject drugs living with HIV only one received antiretroviral therapy.

So what can we do? Why do people not get tested and subsequently present late if at all? I'll try and answer these questions by presenting the work of the HIV in Europe Initiative. This is a PAN European initiative and its objectives are to ensure that HIV patients enter care earlier in the course of their infection and to study the decrease in the proportion of people living with HIV presenting late for care. There was a kick off conference in 2007 in Brussels with some 300 participants and a technical follow up meeting in Stockholm, in November 2009.

So how does the initiative work? It is a network of stakeholders sharing best practices and using this evidence to address issues including barriers to testing and late presentation. And there is a key political advocacy component to this work that has had great success, as I will demonstrate shortly. There's a steering committee of 10 members with five organizations as observers and two co-chairs. There's representation from patient advocacy groups, policy makers, health professionals, public health institutions, such as the ECDC, WHO Europe, the EMCDDA, the Global Fund, and the CDC.

The HIV in Europe Secretariat has three arms; the operations centers of the Copenhagen HIV program in Denmark,

advocacy as lead by the European AIDS Treatment Group in Brussels and finances are run by AIDS Funds in Amsterdam.

In November last year after, after extensive lobbying efforts, the European Parliament passes a joint motion for a resolution on HIV/AIDS early diagnosis and early care. The wording was based on the call to action from the first HIV in Europe conference held in Brussels in 2007 and is worth noting that the European Commissioner for Health participated in that conference.

I will now, given the limited time, fairly rapidly present five studies initiated by HIV in Europe or in the case of the Stigma Index that the initiative contributes to.

These five studies are based on the key barriers identified at the 2007 Brussels conference. Firstly measuring the problem; how to define a late presenting person. Surveillance on the extent of late HIV diagnosis is complicated. More than 20 different definitions are used across the region.

A common definition is as essential in order to establish a baseline expected range of late testers that can be compared with coverage data and to monitor trends over time and to make comparisons between countries and regions. HIV in Europe seeks to identify and begin implementing a unified definition in partnership with key stakeholders. A consensus definition was presented at the HIV in Europe 2009 Conference

in Stockholm and the EX Conference in Cologne in November last year.

Late presentation was defined as persons presenting for care with a CD4 cell count below 350 or presenting with an AIDS defining event, regardless of the CD4 cell count. This was published in the Journal of HIV Medicine in June of this year. Thank you to Professor Yuns Lungran [misspelled?] and colleagues for sharing this slide. I would ask the audience if the rates of late presentation in Western Europe are as high as they are in this map, 30-percent, 41-percent, 52-percent, how high do you think they are in Eastern Europe, where an even greater number of undiagnosed live?

The second study is on the estimation of the undiagnosed population. A working group on estimation of HIV prevalence in Europe has been convened by Andrew Phillips at UCL in London. A first outcome is a guidance document for countries on minimal data requirements and available methods for estimation of the number of people with HIV.

This will be published as a review in the Journal AIDS, congratulations and I hope that we will work to implement it. The document outlines all available approaches and provides the necessary guidance for using them so countries can start making development calculations. This is a first step towards a coordinated European approach.

The preliminary conclusions is that the methods that countries apply depend on the data sources available. Basic surveillance data needs to be improved in order to implement as many approaches as needed at the country level.

The third study is on indicator disease guided testing. This is an approach by which health care practitioners can be encouraged to test more patients based on suspicion of HIV. There is a pilot phase of surveys to better define the methods to determine which diseases and conditions are indicators for an HIV prevalence of greater than 1-percent.

It was launched in May, 2009 with eight diseases. As of the 15th of June, 1,428 out of 7,000 persons were enrolled in the surveys and it is expected to be completed by the end of 2010. It focuses on co-morbid conditions like Lymphoma and Hepatitis C, where there are missed opportunities to offer and HIV test.

We need to remember that many countries, most patients presenting late with HIV have been in contact with the health care system prior to being diagnosed. This figure shows the number of people from 14 countries enrolled per indicated disease as of June this year.

More patients are enrolled with Hepatitis and SDIs than with the rarer diseases like Lymphoma, Septicemia and Dermatitis, where the number of patients seen is lower and where recruitment and offering of an HIV test has proven to be

more difficult. It is too early to present results on the number of persons testing positive but a number of people have tested positive, showing that the surveys have an effect.

The fourth study of the initiative is the people living with HIV Stigma Index. The Index presented in 2008 by the Global Network Living with HIV/AIDS on behalf of the founders the International Community of Women Living with HIV, the International Planned Parenthood Federation and UNAIDS, aims to build the evidence base for understanding stigma and discrimination experienced by people living with HIV.

HIV in Europe supports the implementation of the Stigma Index in Poland, Ukraine, Estonia, Moldova and Turkey. Poland and Turkey have poster presentation at this conference and a work shop on the implementation of the Index in Eastern Europe and Central Asian countries has been held.

An additional set of questions specific to the issues of testing and treatment in the region have been agreed on. Country reports and a report examining the effects of stigma and discrimination on access to testing and treatment will be available by the end of this year.

The last study is on the criminalization of HIV. This pilot study consists of an analysis and evaluation, of the HIV transmission and exposure laws in five countries with different legal approaches; Hungary, the Netherlands, Sweden,

Switzerland, and England and Wales, and is led by Matthew Wheat from the University College of London.

A discussion and issues paper on criminal liability for exposure and transmission of HIV is just about ready. And the development of a larger scale study of legislation in all European countries and the development of a online registration database is being discussed.

So what next? Firstly we should not forget that only 23-percent of the people in need of antiretroviral therapy in low and middle income countries in Europe and Central Asia are on antiretroviral therapy. This is compared with 44-percent in Sub-Saharan Africa.

Concretely the HIV in Europe Initiative suggests to support the implementation of the consensus definition of late presentation and use of multiple methods to estimate the number of undiagnosed. To initiate audits to evaluate whether HIV testing is being conducted in situations where there is an obvious indicator, and if not, why.

To increase interaction and raise awareness among clinicians within different specialties and implement indicator disease guided testing. To develop and implement evidence based strategies to reduce the barriers to testing due to stigmatization, discrimination, and criminalization and to stimulate health professionals, policy makers, civil society

and people living with HIV to advocate together and to collaborate more.

People will only get on and stay on treatment if we devote much greater attention to human rights, community mobilization, and creating and enabling environment.

This is the Initiatives website, check it out. And again, I'm honored to present work of so many collaborators. They're amazing people working all over the region to help people stay alive, thank you [Speaks in Foreign Language] [applause].

NATALIYA LEONCHUK: [Speaks in Foreign Language]. Thank you so much for your presentation, for your short presentation. [Speaks in Foreign Language].

VANDA NOVITSKA: My name is Vanda Novitska [misspelled?] I am from Austria Center in Eastern European Women's Network for Sexual and Reproductive Health and Right.

I have a question to two presenters in fact; while looking at the presentation we didn't hear anything about women and gender issues and HIV pandemic. We know very well that the HIV pandemic in our region is growing very fast among women and apparently almost 45-percent of women have contracted infection, especially young women.

And I wonder whether you identify this as a problem that gender inequalities and in equal status of women in our societies feed that transmission and whether you are doing

something to also address spreading infections among women? Thank you very much.

ANNA SHAKARISHVIL: Thank you for the question and I apologize for having only 20 minutes to cover all the aspects of both the epidemic and the prevention itself, so it was quite a task and I apologize for not mentioning it but it's simply because of the time constraints.

But you are absolutely right; we're seeing indeed quite a feminization in the region, especially in the Eastern European and Central Asian region, although I must say that for some countries it's hard to say where the data are coming from and how to interpret those.

But you are right, at least I can say, in the countries where I know better the, and I have the information on, what is really alarming lately is that we see increasing issues around, both within the community of drug users for instance. You know we see much higher level of stigma discrimination towards female drug users than towards males.

They are different data, I don't want to go into much details. Secondly it is pretty much often known drug using female sexual partners of male drug users that we see sexual transmission in. There are much more adolescent girls who are reported to have HIV etc, so it's definitely an issue and it is essential that gender context it brought into this and it's not

only Africa and Asia. In our country there are definitely inequalities.

Across quite many countries in the region, in Central Asia especially, so I'd be happy you know to talk to you later on.

NATALIYA LEONCHUK: [Speaks in Foreign Language]

RHAMAD ISH: Thank you very much. Good morning, my name is Rhamid Ish [misspelled?] I'm from WHO Regional Office for Europe. It's more a comment for both speakers. I would have expected more attention to the issue of treatment access in Eastern Europe.

As it was shown by Jeff and this is the worst performance of a region of all parts of the world and I don't think it's an issue of clinical management as much as it is about some basic obstacles to access to treatment. Either through in availability of treatment or through obstacles for people living with HIV to access what is available.

And also there was some interesting sessions in this conference showing the modeling data on the impact of universal access to ARVs on the prevention and I think that in this part of the world we should also pay attention to that dimension of it, thank you.

MICHEL KAZATCHKINE: Actually thank you for that comment because I was also going to turn to you Jeff, I was very surprised by the slide saying that the issue is not really

one of access for those who have been diagnosed. That's certainly not true in Eastern Europe for people who use drugs, so could you please comment?

JEFFREY LAZARUS: Yes, thank you Michel, I quote the ECDC report, the special report from the Dublin Declaration, but I also added that the enabling environments are lacking for drug users, for men who have sex with men, for sex workers, so it's actually not as simple, I think, as it was stated in the report itself. So, I'm sorry if that didn't come across clearly. I mean there are multiple aspects to accessing treatment. One is, of course, knowing your status, another is being able to come back to the center aware of your status and access treatment, given the reason you got HIV in the first place.

Because of the discrimination against injecting drug users, it doesn't always help to know you're HIV positive, and that's why I added the words of Anya Sarang, from Monday, that what is the incentive given this discrimination to go to a health care center in the first place and I would even to return knowing your status for treatment, if you're going to be discriminated against.

NATALIYA LEONCHUK: [Speaks in Foreign Language].

SHONA SCHONNING: [Speaks in Foreign Language].

ANNA SHAKARISHVIL: [Speaking in a foreign language]

JEFFREY LAZARUS: [Speaking in a foreign language] I would like now to call fivepeople from the community and civil society to speak, each of them for three minutes, and in order to save time and to give the people the opportunity to express themselves at their best I would suggest that they just introduce themselves as they are prepared to speak and then we'll open it for a discussion. Roman?

OMAN DUDNIK: [Speaking in a foreign language]

JEFFREY LAZARUS: [Speaking in a foreign language] Roman. Ophelia?

OPHELIA HAANYAMA ORUM: Thank you very much. My name is Ophelia, I'm from Sweden, I work for The Noak's Ark Foundation. I think HIV is one of those things that illustrate mobile people. Imagine you started somewhere in the world with one person. It has now, few years later traveled around the world, a few years ago you were just in a conference talking about South Africa.

A few years ago you were in a conference talking about just homosexual men. A few years ago, you are at the conference talking about sex workers, but now it's so mobile that it has reached every continent, every person. There's no individual in the world today that has not been touched by one disease and that is HIV.

How come we are only trying to find solutions now? When did we miss the point? At one point did you realize that if someone moves from Central Asia to Sweden, they're only going to have sex with people from Central Asia? If that was possible, HIV would still

be among Africans, among homosexuals, there would be no one having sex with anyone else.

What are we supposed to do, how would we tackle that specific fact? Because when people move from Central Asia to Eastern Europe to Western Europe to Southern Europe, apparently they're leaving that community they moved to. They have sex in that community they stay in. Nobody is asking for documentation when they're having sex, I haven't heard that one. No one goes, "Before we have sex, please can you give me your national insurance number?" They don't. As long as we don't realize that being documented is not the issue.

Being mobile is actually the issue. We wouldn't be here today, fighting for who gets treatment and who doesn't if we had acknowledged that it's a disease for the people. Whether they are mobile or not, whether documented or not, and my question to the experts is "What is the plan?" To the audience, "Can you do anything to help?" I think in this audience I could maybe almost the only black woman, HIV positive, but I'm in Vienna! That is mobile.

I work in Sweden that is mobile. My husband is Danish that is mobile. I mean how much more do we need to sort this problem out? I would be very happy if anyone has any solution on how to reach everybody. Everybody has rights to universal access. You know they come up with all these good words like universal access but what does it mean? I don't even understand it, so I'd be very happy if anyone

could come up with a good discussion or solution and thank you very much.

JEFFREY LAZARUS: Thank you Ophelia for raising this discussion here, this is the right place, Vito?.

VITO GEORGIEVSKI: [Speaking in a foreign language]

ANKA GRZYWACZ: Hello, thank you for inviting me to talk about sex education in Poland. My name is Anka Grzywacz, I'm from Poland, I'm a sex educator in the group of sex educators PONTON, and I cooperate with Astral Network of organizations from Central and Eastern Europe working on sexual well and reproductive health and rights. Let me very brief, but I will start with a quote from a teenager who called our sex education hotline last year.

She said "My boyfriend doesn't understand when I suggest that we use protection. I can't just ask him, I'm afraid I will get pregnant. Please tell me how do I talk to him?" This quote tells us a lot about the state of sex education in Poland. First of all, young people are, especially young women are not aware that they can contract HIV virally, only worry about unplanned pregnancy.

The second thing is the lack of sex education means that they do not have any skills to negotiate condom use with their partners. Sex education could solve this problem, at least partly but we have very strong church influence, Roman Catholic Church with Polish bishops influencing laws that are

being created in Poland, we have no chance of reforming the system.

We will continue to have bad books which tell us that homosexual people are sick. We will have teachers who are unprepared to talk about sexuality. With our groups, the groups like mine are really trying to change the situation but we are a small group of volunteers. With Poland entering the EU, we have lost many chances of receiving funds. It is pretty much difficult to get funding, especially for organizations combining the sexual health, reproductive health with HIV and AIDS prevention.

I would really suggest that we rethink the way these organizations like mine, in the countries like Central and Eastern Europe are funded and I would really suggest that we also try to focus on women, and especially young women and try to empower them to be able to protect themselves from HIV. Thank you.

FEMALE SPEAKER: [Speaking in a foreign language.]

MALE SPEAKER: [Speaking in a foreign language.]

FEMALE SPEAKER: [Speaking in a foreign language.]

MALE SPEAKER: [Speaking in a foreign language.]

MALE SPEAKER: [Speaking in a foreign language.]

MALE SPEAKER: [Speaking in a foreign language.]

MALE SPEAKER: [Speaking in a foreign language.]

FEMALE SPEAKER: Here please.

MALE SPEAKER: [Speaking in a foreign language.]

ALINA DIMITRIO: My name is Alina Dimitrio [misspelled?] from Romania, I represent the people living with HIV in Romania. I want to underline again the stuck out we are dealing with starting with April [misspelled?]. We have pregnant women without treatment, and there in the last semester, we have babies without syrup, we have our teenagers affected in their childhood, on the Ceauşescu period and now are 22, 23 and maybe they are on the last combination of treatment and they are without treatment.

We have nine people who are eligible to start treatment, early diagnosed and not late and they can start treatment. The problem is, they decentralized the system, the tenders one year and a half ago, and also the government approved just 60-percent of the budget for this year.

There are rumors they will centralize again the tender, and we hope this. Until now, we have this problem and I want to ask everybody who can help us to do this because the government condemns the people living with HIV/AIDS in Romania to death. Everybody who can do something on this direction, and they are not doing this, they participate. Also we have big problems with prevention programs. It was a slide in Russian language but my colleague from Moldova translates for me.

It was like the government gave a lot of money for our prevention program, it's not true. They gave us, the Minister of Labor, not the Minister of Health just 7,000 syringes for a year. We gave these syringes in one night with two ambulances. This is the truth. This is what is happening in Romania. Thank you.

JEFFREY LAZARUS: Thank you, and thank you for raising the problem. This is not the first time in this conference that we hear about Romania. I was in a session two days ago where those issues were raised so thank you for raising your voice. Microphone #3.

FEMALE SPEAKER: [Speaking in a foreign language.]

JEFFREY LAZARUS: [Speaking in a foreign language.]

[END RECORDING]