



EATG satellite: "Treating HIV positive people injecting drugs in Europe: a mission possible" (EACS 2009, Nov 10-14, Cologne)

Presentation by Nikos Dedes, EATG, chair of the Policy Working Group

“Ladies and gentleman, I would like to thank the organisers for giving me the opportunity to address this audience in the opening session. I was pleased to accept the invitation by Juergen Rockstroh and Peter Reiss as a recognition of the role of community-based organizations in the fight against HIV/AIDS. When I am given opportunities to speak I usually say that I will contribute a few of my thoughts since no one can possibly represent or do justice to the variety and expertise of community voices. But I know that I speak for all when I start by thanking all of you, our doctors, for being the one ally standing next to us throughout the years. Oftentimes you are the only ones who face the challenge of addressing the breadth of psychological, emotional and social problems that PLHIV face. All of this in addition to the physical problems caused by HIV infection.

This is why I stand today before you to ask you to join forces in an advocacy agenda that we can identify together and pursue, both on our national level and through EACS on a European one.

So how are things really going in Europe? After all, is it not one of the most privileged regions of the world?

When we see Europe on the global map of Human Development, one sees that the European Region is doing quite well. I should note that for the World Health Organisation, the Regional Office of Europe considers together the 53 countries that include the Independent States of the

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Former Soviet Republics of Central Asia. I prefer the Human Development index to purely economic indicators since it is putting people at the centre.

From the four strata of Human Development defined by UNDP as “very high”, “high”, “medium” and “low”,

44 of the European countries are in the “very high” and “high” strata and only 9 in the ‘medium’. Nevertheless we know very well that in the region we have different realities and a big discrepancy in access to treatment.

This map of 2003 shows a situation of very low coverage in the majority of countries that are also the ones with the highest HIV prevalence.

The recent WHO Progress Report to Universal Access found that the European countries with low and middle incomes have an unacceptably low ART coverage rate of 23%. Not only that, if one sees the trends in reported new HIV cases by the ECDC and WHO we are continuing to see a steady increase in the EAST. Below this is the apparently less alarming graph of the West which still shows a marked upward trend since 2000 after 5 years of stability.

These new cases are most likely rising infections in men who have sex with men, though the continued rise in the “undetermined” category is of concern. It may not just reflect late case categorizations, but also the level of stigma and discrimination that certain groups face and who therefore avoid notifying the route of transmission. Transmission in some groups may therefore be underestimated.

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Coming back to the region, injecting drug use is the key vulnerability factor that remains the key driving force of the HIV, hepatitis C and Tuberculosis epidemics. Treatment and prevention access by IDU is disproportionately low.

In this state of affairs the EU Commission on the 26th of October published its next 5-year Strategy Plan and I have to admit that this time the Commission did an excellent conceptual job.

First of all it started by identifying the objectives of our response and in boiling them down to three apparently simple ones, did us a favour.

These are:

- to reduce the number of infections taking place in Europe,
- to improve the access to treatment & prevention and
- to raise the quality of life of PLHIV.

While they may seem self-evident, what's important is to use evidence to understand what drives the increase of the epidemic. Only evidence will tell us what works and what does not. Already in the text of the Strategy Plan it becomes clear that according to the commission, contrary to what some officials and politicians may think, what makes things worse is not the influx of infected people to Europe, it is the travel and residence restrictions that make them hide. It is not the Harm Reduction programs with substitution treatment and syringes exchange programs but the zero tolerance and police violence driven by faltering legal framework and policies.

What would make things better is not increasing criminalisation of people living with HIV and of the practices of the vulnerable and most at risk groups, it is a legal and social framework that offers protection and reduces the barriers to access and helps people seek testing and treatment.

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I know that this audience has both the intellectual capacity and exposure to the realities of HIV that the above statements are self-evident. It is our obligation, the doctors, researchers and ours, the community advocates, to speak with one voice and ensure the implementation of the correct policies and programs.

So what is it exactly what we need in order that we reverse the epidemic? What should we advocate to be in place?

I believe what are needed are the following:

- 1) Good surveillance. One needs to “know one’s epidemic” and be able to measure the impact of our interventions
- 2) We need Research that informs and provides the evidence for those interventions
- 3) We need strong Monitoring & Evaluation mechanisms that ensure accountability and help the authorities and all stakeholders to make the best use of the resources.
- 4) We need Political leadership. This sometimes comes as a pleasant surprise but more often is the result of advocacy by leading physicians and pressure from the community
- 5) We need to secure the necessary funds. . But unless we demonstrate the need for programmes and the evidence for their effectiveness, resources cannot be secured in a competitive environment, especially in fiscally difficult times.
- 6) And as the title of my speech suggests, together we shall stand much stronger in the fight.

First of all it is unacceptable that Europe has one of the worst HIV surveillance in the world. While, thanks to the creation of ECDC 5 years ago things started to change, many countries and regions of the world have better knowledge than Europe of the number of undiagnosed, figures of incidence or figures of prevalence in the various risk groups. In some countries the health authorities even know the prevalence or incidence by region, as you can see here in a slide by the National AIDS Control Program in Kenya, or even by city district as we can see in this slide in

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Washington, DC (the District of Columbia). This reminds me of the superlative job of Julio Montaner in British Columbia, who we will hear from tomorrow. With this kind of data health authorities and NGOs can focus efforts and use the resources in the optimal way.

On research it is clear that we need more nationally supported research, but more so a coordination at EU level so that we avoid unnecessary duplication of efforts. We need more biomedical research through cohorts, clinical studies and basic research but we also need to focus on the neglected social sciences, Public Health and operational research. Given the wealth of new treatments and evidence-based prevention that we have identified over the years, it is clear that if we fail in our response to the HIV epidemic, it is the result of social and structural problems which we need to study and understand better.

New Prevention Technologies or strategies like microbicides and pre-exposure prophylaxis will hopefully help in the future and we must never give up in the pursuit of a preventive vaccine. But we should make sure that funds are used reasonably and proportionately.

For the research I will use two examples of things we want more of. One established and one new.

For the established I take the EuroSida Cohort. There are also excellent similar national examples like in Switzerland and the Netherlands. EuroSida has existed now for 15 years and has produced a recognized wealth of data that has vastly contributed to improving clinical practice. It is also a world leading cohort.

The relatively new one is NEAT, the European Clinical Trials Network, our European equivalent to the ACTG in the making. In the map you can see the current members and the intention is reach out to many more.

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The project, coordinated by Stefano Vella and the Istituto Superiore di Sanita, is supported by DG Research for 5 years with 44 core partners from 16 countries and importantly includes all national AIDS research networks like the ANRS and the MRC. The objectives are to harmonise research, transfer knowledge from centres of excellence to ones that are less experienced and of course conduct trials. Many of you will participate in the first trial, NEAT 001 which is led by Francois Raffi and Anton Pozniac and is the first example of a trial that is designed by doctors with the participation of patient representatives and will focus on the types of questions that clinicians and patients are interested in.

Starting from the design, which tries to answer strategic questions, to issues that are not adequately captured in industry funded registrational trials like QoL, pharmacogenetics, extensive safety test etc.

The money given by DG Research is not nearly enough for the sustainability of such a network so if we wish to see it grow or if we want to ensure the continuation of the funding for projects like EuroSida. We must knock on the door of the Commission and the European Parliament which co-decides on budgets and priorities.

I now come to a topic that is rather elusive but it is very close to my heart since I realize how much, we ourselves, in the community oftentimes fail to implement it. But when the state fails to do it, it is disastrous.

Monitoring & Evaluation should be part-and-parcel of any program and we might just as well review the whole National AIDS plan in each country and demand yearly reports. The parliament is the perfect body that could review it and exercise control. Monitoring & Evaluation helps improve performance and throw away what does not seem to work.

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Measuring by itself improves performance, measuring and publishing improves performance even more.

Consumer Power House published recently the Euro 2009 HIV index that measures performance in four areas for the EU countries. It assigned a figure for each indicator and adding up the figures resulted in a visual depiction of performance that left very few happy other than Luxembourg and perhaps Malta and Switzerland who ended in the top three positions. But one should not see such exercises as a competition but rather focus on one's country and those red or yellow lights and work to turn them in to green.

The last EU presidency to identify HIV as a priority was Germany and the ministerial meeting was graced by Chancellor Merkel herself. That was one of those pleasant surprises that I spoke of before. Many of the necessary policies to stop the epidemic are politically controversial. Harm Reduction programs, support for migrants, repeal of criminalization laws. For all these measures, we need to reach out together to the highest political figures to convince them when they think otherwise or to support them to take the right choice when they recognize what is right. We also have a responsibility to help regions outside ours and put pressure on our governments to provide the proportional assistance to the Global Fund to achieve the target of Universal Access to Prevention Treatment and Care.

For examples of partnership I would of course start from EACS itself who over the years has worked with the EATG, notably in the EACS Guidelines, but the most prominent one is HIV in Europe. This has been recognized by the conference co-chairs who invited the next speaker, Jens Lundgren, co-chair and leader of the initiative. HIV in Europe is a collaboration of doctors, patients and policy makers.

And its objectives were to:

- 1) Highlight the number of undiagnosed

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- 2) Identify the political, structural, clinical and social barriers to optimal testing and early care
- 3) And to promote best practices

What I want to emphasise, from my part, is how following the first conference we went to members of the European Parliament, explained the outcomes of the meeting, and they turned our call to action into a Parliamentary resolution that actually passed with an unprecedented majority.

Similar initiatives took place in many countries and led to a resolution on testing in Italy and the creation of cross-party groups in Portugal and actions in Spain and Belgium to pursue the resolution's aims.

I hope I have illustrated the need and the opportunities to work together and the indispensable role that you can play as advocates for evidence based policies and programs both nationally and in the region!

Thank you"

The European AIDS Treatment Group (EATG) is a NGO at the forefront of the development of the civil society response to the HIV/AIDS epidemic in Europe. The EATG is a European patient-led advocacy organisation that represents and defends the treatment-related interests of people living with HIV and AIDS. Its mission is to achieve the fastest possible access to state of the art medical products, devices and diagnostic tests that prevent or treat HIV infection or improve the quality of life of people living with HIV, or who are at risk of HIV infection. For more information, please visit www.eatg.org