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Speech at the opening ceremony of the EACS Conference
Barcelona, 21st October, 2015

Good evening dear Friends and Colleagues,

My first sentences are those of gratitude. On behalf of the European AIDS Treatment Group and the communities of people living with HIV in Europe, I would like to say thank you to the European AIDS Clinical Society and its leadership for the exemplary cooperation with the community of people affected by or at risk of HIV. I have the privilege to work with many different patient organisations from many different disease areas, and I can assure you that this cooperation is rare and unique - even though we all may take it for granted. So thank you again.

I will not bore you with numbers and tables; that would be preaching to the converted. I know you know that I know the numbers as well as you do, and we have the next few days for exchanging and discussing figures, tables, numbers, results, and - most importantly - the interpretations of these numbers anyway. I am here today to talk about the perceptions and issues of the community of people living with HIV.

A lot has happened in the last two years since the previous EACS Conference in Brussels. We know now for sure that early treatment is beneficial for individual and public health, and that it is the thing to do. We know that PrEP works, and that it is an effective means in the array and toolbox of prevention tools. It is a unique moment because a sensible combination of treatment scale-up and prevention, including biomedical options, can slow down and stop the HIV epidemic in Europe and elsewhere. The UNAIDS 90-90-90 target is truly within reach, or at least theoretically reachable.

We know now for sure that, for the first time, hepatitis C can be cured in almost 100% of cases in Europe. A wide selection of treatment options have emerged, and you will see also in the coming days how much work, research and development have been going on in the field of HCV. Even if it is still lagging behind the “older sisters”, research and advocacy in tuberculosis are growing. Did you know that TB used to be called ‘morbus hungaricus’, the Hungarian disease? TB is rampant again in Central Europe.

We know more than ever about treatment cascades and continuums. We have a relatively good understanding of the modern face of the HIV epidemic, we increasingly acknowledge the concept of a syndemic - a synergistic concurrence of physiological, psychological, mental conditions that come to an intricate interplay when we consider HIV.

There has been a lot happening in the communities of people living with HIV, too. A whole new lot of knowledge and information has accumulated in the community about harm reduction, chemsex, the use of recreational drugs in a sexualised context, a new and alarming phenomenon that has become part of the scientific vocabulary thanks to the tireless efforts of my peers in London, Berlin, Barcelona and Brussels.

Being a user is still stigmatising, but there is a growing number of people who see drug use as a health issue rather than a criminal deed. We are getting ready for the United Nations General Assembly Special Session on Drugs, and the International Harm Reduction Conference in Kuala Lumpur has discussed key issues around HIV, too.

Some tremendous, and sadly exceptional, results in treatment and harm reduction were achieved by HIV community members in Russia and the Ukraine despite all the hardships, and with considerable help from people like Michel Kazatchkine or some groups of people at UNAIDS, the WHO and ECDC.

There has been particularly much work going on around prevention in the community of people living with HIV. PrEP has been high on the agenda because by promoting PrEP and proven prevention strategies, we, people living with HIV can also effectively contribute to curbing and eventually stopping the HIV epidemic, thus living up to our responsibility.

Please note in this context the recent publication of the HIV Prevention Position Paper developed by members and staff of the EATG, which describes the current state of play, challenges and possible solutions in the field of prevention. Electronic copies are available from any EATG and AVAC representative at the conference. A beautiful piece of science done by the community for groups beyond the community.

Let me quote one key concept from this position paper: “There is no such thing as a ‘high risk person’ or ‘high risk group’. There are certainly key affected populations, but behaviours, not people, confer high risks of acquiring or transmitting HIV, and individuals may move in and out of HIV risk situations as their lives change. HIV prevention therefore needs to provide access to the right combination of information and of biomedical, behavioural and social interventions to the right people at the right time in the right context.”

Look, I am a white, educated, middle-class, homosexual man. My life is that of privilege. And yet here I stand with HIV, HCV, depression and a history of substance use.

Some would simply call me a weak person. Some others would say that it is my fault. Others will see me as a criminal. But data from the ECDC show that the HIV and

HCV epidemics are constantly growing in this particular group in Europe: young men having sex with men. Except for a few centres of excellence in London or Berlin, the issues of young homosexuals are simply swept under the carpet, while the community is in a really bad shape. And there are many more like me, and there are drug users and sex workers, prisoners, migrants with or without a clear legal status, and trans* people across Europe who live with or are at risk of HIV. Many will never reach care. According to one source, twenty-two thousand people died of AIDS in Russia in 2013. People who don't have access to the care and medication that is a matter of fact to almost all of us in this great room.

Despite the need for an individualized, no-blanket approach, we also know that the concept of key affected groups does make sense. Gays in Europe smoke more than the general population. Gays drink more. Gays use more recreational drugs. Women are underprivileged across the research and treatment continuum.

When will there be enough people like me to admit that this is a systemic problem that needs systematic solutions?

So before we get carried away with how good the situation seems to be in Western Europe, we should realise that health care systems in Eastern Europe, in fact even in the whole of the European Union are fragmented and often siloed, which means that patients will have to go to different specialists and clinics with their non-HIV related issues. With a high degree of still pervasive stigma and discrimination against people living with HIV amongst service providers, this means that patients either don't get treated, or that HIV specialists get to deal with diseases and health conditions that they don't know much about.

One of my peers, a 62-year-old grandmother with HIV was refused an eye examination because she admitted to her HIV status. A major human rights NGO had to sue the National Clinical Centre for Stomatology in Hungary because they outright refused to treat people with HIV. This is not a rarity at all - just look beyond Western Europe. And I do not even start talking about harm reduction, or rather the lack of it, in Russia and Central Asia.

We need your help to reach out to specialist physicians in other disease areas in order to make sure that there is an integrated approach to the health of people living with HIV. We need your help to bring clinical trials to more clinics and centres across Europe. The EATG has launched a project to compile a registry of potential trial sites because - even if it seems really embarrassing - clinical trials remain a key vehicle for many to access life saving treatment, especially with the prohibitive prices of HCV and HIV treatment that must be offered to all. And we need to focus more on women, too. Despite all efforts, women are underrepresented in clinical trials, in patient organizations and science alike.

A study of the ECDC on the monitoring of the Dublin process proves that the last 10 years since Dublin have seen a declining budget in the response to HIV on the level of the European union and the Member States alike. Health in general, and infectious diseases in particular, are not a priority for the current European Commission. We need more than words and promises: The numbers are telling. We need to put Europe back on the map of the global HIV response. We do not want to participate in a twisted race and competition for funds and attention - this is simply not fair! We need to look into structural problems and make sure that Europe is in the forefront of the treatment continuum just as it is pioneering in biomedical research. We need to stop the unhealthy competition across Europe that is being brought about by non-transparent and profit centred pricing and intellectual property policies.

Before you roll your eyes that I am a naive lunatic, I want to assure you that the community of people living with HIV is here to help. We know each other and we operate on a different level of trust and understanding across our communities. We have invested thousands and thousands of euros and an immense number of volunteer working hours into developing proposals and solutions, workable models that are cost efficient and economically sound. We have done and are doing our homework on our end just as you physicians and researchers have been doing yours.

The consensus of the community feedback session at the last EACS conference in Brussels was that the science is largely done, we now need to make sure that medication reaches the people. We understand now that, with PrEP and early treatment initiation, perhaps more medication needs to reach more people, and more and different interventions are needed if we are to reach the target of stopping the HIV epidemic. Together we have sufficient leverage to convince politicians and business decision makers. Otherwise Europe will fall behind in this field.

Viruses and diseases know no borders. Research and community advocacy and activism in HIV have been models and pioneers in the history of health care and epidemiological response. Together we can show the world that this is also feasible when we stop the HIV epidemic in Europe. You and us together - the ones most affected by HIV. Help us put Europe back on the map.

Thank you for your attention.