THE FIGHT AGAINST HIV AND HEPATITIS: OUR VISION OF A EUROPE FOR HEALTH

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Significant progress has been made in addressing HIV and hepatitis in terms of knowledge, treatment and tools. International commitments have also been made to put an end to these epidemics[1]. However, the European Union and Europe more widely[2] continue to face many challenges in terms of access to prevention and care, and respect of fundamental rights.

A highly active HIV epidemic

In 2017, for the region as a whole, 160,000 people were diagnosed HIV-positive, that's 20 per 100,000 inhabitants. More than half (53%) were in advanced stages of infection. Populations vulnerable to the epidemic (i.e. drug users (DU), men who have sex with men (MSM), sex workers, detainees, migrants, trans people) are disproportionately represented among new infections: 30% are MSM, 15% are DU[3]. But, to achieve the health-related sustainable development goals in the region, these new infections must be reduced by 78% by 2020[4].

Hepatitis C is wreaking havoc

In Europe, 14 million people are chronically infected with hepatitis C virus (HCV) and 112,500 die each year[5]. Among them, drug users are particularly affected by this infection which is transmitted mainly by contact with blood. Yet, effective drugs exist, which can cure 95% of these infections.

A worrying situation in Central and Eastern Europe

While this part of Europe accounts for 80% of new HIV infections and HCV prevalence reaches up to 6%, continuity of care is compromised by disruptions in medication supply and excessive prices to the point that drugs are not accessible. This situation, at the intersection of individual health, public health and equal rights, all too often results in a selection of patients to the detriment of vulnerable populations, whose health continues to deteriorate. In particular, there is an increase in cases of tuberculosis among people living with HIV.

Criminalised and discriminated populations are particularly prone to contamination

Nearly half of those infected with HIV are from vulnerable populations[6]. Repressive policies in some countries of Central and Eastern Europe, aimed against these populations, relegate them to exclusion, where risk taking is more frequent. These same laws promote discriminatory practices against these populations when they attempt to access health care and prevention systems.

Treatment advances that do not always benefit those who need them

The tools exist to end these infections. It involves joining screening with combined prevention: access to treatment for those infected to prevent the spread of infections; condoms, post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP) to prevent HIV-negative people from becoming infected with HIV, the rolling out of harm reduction strategies (HR).

❶ Notably for HIV (UNAIDS): 90% of people living with HIV should know their status, 90% of these people should receive treatment, and 90% of them should have viral suppression. For HCV: World Health Assembly endorsed the *Global Health Sector Strategy (GHSS) on viral hepatitis 2016-2021*. The GHSS calls for the elimination of viral hepatitis as a threat to public health by 2030. ❷ According to the WHO definition of the Europe region. ❸ Source: www.ecdc.europa.eu/sites/portal/files/documents/hiv-aids-surveillance-europe-2018.pdf ❹ Source: www.ecdc.europa.eu/en/publications-data/hivaids-surveillance-europe-2018-2017-data ❺ Source: www.euro.who.int/__data/assets/pdf_file/0009/377253/fact-sheet-hepatitis-c-eng.pdf?ua=1 ❻ Source: www.ecdc.europa.eu/en/publications-data/hivaids-surveillance-europe-2018-2017-data

A EUROPE WITHOUT AIDS NOR HEPATITIS IN 2030 IS POSSIBLE! IT'S WHAT WE BELIEVE, IT'S WHAT WE WANT!

Infections circulate and know no borders. The European Union has acknowledged this[7]. This is why the development of pan-European actions is essential to organise a coordinated and effective response.

To achieve sustainable health goals across Europe by 2030, stakeholders, civil society, healthcare providers and policy makers need to work together.

We want

We, civil society organisations, patients' associations and affected people, want to see a Europe for Health firmly established in the European Union, its member states and neighbouring countries:

• Strengthening the social dimensions of sustainable development in order to reduce social inequalities, build sustainable, universal and more equitable health systems and improve health outcomes for all,

• Respectful of human rights, promoting universal access to health for all, and strengthening the capacity of states and citizens to access the treatment and prevention tools needed to end the epidemics of HIV, hepatitis and tuberculosis. A Europe that works against discrimination related to infections, sexual orientation, gender identity and lifestyles,

• Avant-garde, driving and coordinating innovation in response to these epidemics, both in Europe and internationally,

• Making space for stakeholder involvement through the sharing of practices and experiences, and facilitating their work with citizens to meet their needs.

We ask for

The European Union and its institutions (Parliament, Commission and Council) must assume a leading role both with members and neighbours. We ask it in particular:

• **To increase its development aid** through an increased contribution to the Global Fund to fight HIV, tuberculosis and malaria and through the establishment and allocation to health of **the Financial Transaction Tax**,

• **To implement a migration policy respectful** of people, with appropriate care, including health issues,

• **To make its drug policy respectful of the health and rights of consumers,**

• **To ensure the transparent and fair pricing of medicines** so that all citizens of Europe can access medicines without discrimination due to their financial means or those of their national health system.

Coalition PLUS Platform Europe and the signatory organisations of European civil society, call upon European institutions and future elected members of the European Parliament to support these demands and make them a reality.

[7] Decision 1082/2013/EU on serious cross-border threats to health.

INTERNATIONAL SOLIDARITY: EUROPE MUST ASSUME ITS ROLE

Activist march during the International AIDS Conference in Durban, South Africa, 2016.

The HIV/AIDS epidemic continues to wreak havoc

In 2017, 1.8 million more people were infected and nearly one million died worldwide. While the epidemic is declining, 41% of people with HIV still do not have access to treatment[8]. While solutions exist, the goals, adopted by the international community[9] and UNAIDS[10] to achieve the end of the epidemics remain distant.

Beyond political will, structural problems and the weight of discriminations, it is a question of insufficient financial resources. In fact, UNAIDS estimates that by 2020, $26.2 billion a year will be needed for the necessary actions and treatments, and that a little less than $5 billion a year is needed to fund the response[11].

The stakes are high, because without additional funding to accelerate the fight, the risk of a resurgence of the epidemic is very real. This concerns us all, member countries of the European Union and our European neighbours. In addition, without achieving the sustainable development goal of "Good health and well-being[12]" other objectives, such as the eradication of poverty and malnutrition or the reduction of gender and economic inequalities, cannot be achieved.

An EU commitment to be reinforced to achieve international goals

The European Union and its member states contribute to international solidarity efforts to achieve these goals. Regarding HIV/AIDS, the European Union was the 6th contributor to the Global Fund to fight AIDS, Tuberculosis and Malaria at the last replenishment conference in 2016.

Since 2011, the introduction of a financial transaction tax (FTT) on a European scale has been under discussion. This tax would allow the European Union to collect 19.6€ billion per year[13], more than three times the amount of funding currently missing. Unfortunately, due to the lack of real political will on the part of the heads of state and finance ministers of the countries concerned, this tax is still not implemented.

With regard to development aid, the contribution of EU member states, although above the world average (0.5% of gross national income), remains below the target of spending 0.7% of their gross national income[14].

❽ Source: www.unaids.org/en/resources/fact-sheet ❾ UN, Sustainable development goal n° 3.3: "By 2030, end the AIDS epidemic, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases." ❿ 90% of people living with HIV should know their status, 90% of these people should receive treatment, and 90% of them should have viral suppression ⓫ Source: www.unaids.org/en/resources/fact-sheet ⓬ Source: www.undp.org/content/undp/en/home/sustainable-development-goals/goal-3-good-health-and-well-being.html ⓭ *EU Sees $23.5 Billion in Revenue From FTT*, 14/05/2018, www.bloomberg.com/news/articles/2018-05-14/eu-sees-23-5-billion-in-revenue-from-financial-transaction-tax ⓮ OCDE, "L'objectif de 0.7% APD/PNB – un historique", www.oecd.org/fr/cad/stats/lobjectifde07apdpnb-unhistorique.htm

Significant room for improvement in international solidarity is still possible.
In addition, the announced merger of the 12 instruments for evaluating the Union's external action into one (e.g. development aid, security issues, migratory control, etc.) will make it difficult to monitor commitments made to the poorest countries and the fight against global inequalities.

We want

a considerable increase in official development aid, both from the European Union and its member states, in order to play a decisive role in ending these epidemics and reducing inequalities between countries.

We ask for

- **An increase in the contribution of the EU and its Member States to the Global Fund**, both in amount and percentage during the Replenishment Conference on 10th October 2019,
- **Support to countries in Eastern Europe** and Central Asia that will cease or have ceased to be eligible for the Global Fund to ensure the sustainability of HIV/AIDS and hepatitis programmes, particularly programmes for key populations,
- **The implementation of the European financial transaction tax,** the proceeds of which must finance development aid and international solidarity,
- **Increasing the EU's official development assistance** to at least 0.7% of the equivalent of gross national income,
- **The highest possible degree of transparency and accountability** for its next budget cycle to ensure parliamentary and citizen oversight.

MOBILITY AND MIGRATION: ENSURING ACCESS FOR ALL TO HEALTH IN EUROPE

Demonstration in front of the French Immigration Office to denounce the unjustified refusal of residence permit for care, AIDES, Paris, France, 2018.

Migratory deterrence and repression policies threaten the health of those forced to leave their country because of conflict, political persecution, discrimination, economic conditions or natural disasters. It is now clearly established that these populations are overexposed to the risks of contamination by HIV, hepatitis and tuberculosis because of their migratory routes and the precarious living conditions that mark their first years after their arrival in Europe[15].

A "migration crisis" blown out of proportion

Today, European immigration and asylum policies are marked by cooperation limited to law enforcement, in particular through the Frontex agency, which controls the EU's external borders. Far from coping with a massive migratory flow, the Union welcomes only a limited number of people in exile worldwide: 17% in 2016 according to the United Nations High Commissioner for Refugees (UNHCR), against 30% for Sub-Saharan Africa and 26% for the Middle East and North Africa. And yet, external border control is getting tougher, with the establishment of sorting centres at the main points of entry, and the outsourcing of the management of refugee populations to neighbouring countries in return for financial or diplomatic compensation.
This "migration crisis", exploited for political ends, is fuelling withdrawal and xenophobia, and masks what is really at stake: a crisis in the governance of immigration and asylum reception systems in Europe.

According to the member states of the European Union, the authorities responsible for examining asylum applications do not sufficiently take into account cases of persecution suffered as a result of sexual orientation or gender identity in the native country.

Policies that harm people's health

People migrating to Europe do not always have access to the prevention and care they need, as member states have only minimal obligations in this area. Moreover, although the European Court of Human Rights has recently raised the standard of protection for foreign sick people[16], no European legislation protects them against deportation to a country where they will not have effective access to treatment.
As regards asylum, the Dublin Regulation requires people to submit their application in the country through which they entered the EU, or at least the place where they left an administrative trace. This provision leads people to be deported from one European country to another, sometimes as a precondition for expulsion to their country of origin. The state of health, beyond the physical possibility of traveling, is rarely taken into account during these procedures and the speed of the latter often prevents asylum seekers from claiming this right.

[15] ANRS-Parcours survey in France and AMASE in ten EU countries. [16] Paposhvili v. Belgium, 2016.

Coordination of health systems is insufficient for the amount of people moving around

Today, member states do not offer all the guarantees of continuity of access to prevention and care for the populations who move within the European space, whether to live, work or travel, regardless of their administrative status.

The situation is particularly problematic for the migrant populations most exposed to HIV and hepatitis, including sex workers and men who have sex with men, whose mobility within the EU may be an obstacle to access to rights and health.

We want

a European Union providing a true reception policy with dignified living conditions for all and guaranteeing the principles of non-discrimination in health across the whole of its territory.

We ask for

- **Access to health insurance for all those** residing in an EU member state to access prevention and appropriate care in the common law system, regardless of their administrative status,
- **Effective coordination of social security systems** to ensure continuity in access to prevention and care for mobile populations, irrespective of their administrative status,
- **The EU and its member states to ensure safe migration routes,** in order to protect people forced to leave their country of origin from the violence to which they are exposed during their journey,
- **The establishment of a common European framework** to take into account the specificities of the most vulnerable displaced populations who seek **asylum,** including women and people who migrate because of their sexual orientation or gender identity. Asylum seekers must be able to apply to the country of their choice in Europe,
- **The guarantee of an effective ban on the expulsion of foreigners who are sick** to their country of origin where they do not have effective access to medical care, and for the regularisation of their status for medical reasons.

END THE WAR ON DRUGS IN EUROPE AND IN THE WORLD

Coalition PLUS' campaign: "Just Say No to the War on Drugs" during the International AIDS Conference in Amsterdam, The Netherlands, 2018.

The European Union has consistently affirmed its role as a world leader in the defence of human rights, support for civil society and support for drug use harm reduction programmes, as demonstrated by its 2017-2020 drug strategy[17].

An alarming and worsening health situation

Europe continues to face still very significant and growing challenges for drug users in the context of HIV, tuberculosis and especially hepatitis C epidemics with a prevalence of 61%[18]. The figures show new consumption practices and a worrying increase in overdoses and drug use related deaths (4% more between 2015 and 2016[19]). Political will remains insufficient and misguided to respond to it.

The coverage of risk reduction and opioid substitution treatment programmes is insufficient because of the lack of adequate financial resources and attests to a great disparity both within the Union and with the rest of Europe.

Repressive laws that favour epidemics

Despite initiatives by some countries that have revised their repressive legal framework for a pragmatic approach that has shown positive results, the European Union remains anchored in a repressive approach to drugs and even goes beyond the UN conventions. This has the effect of creating great disparity between the member states and constraining any rolling out of more progressive policies.

Yet the scientific evidence demonstrates the failure of this policy, as reported by the Global Commission on Drug Policy[20], which also demonstrates how the criminal prohibition fuels the very high level of discrimination and stigmatisation of this population in access to health, housing, employment, etc.

17 Source: www.drogues.gouv.fr/sites/drogues.gouv.fr/files/atoms/files/plan-action-antidrogues-ue-2017-2020.pdf 18 Source: www.emcdda.europa.eu/data/stats2018/drid 19 Sources: www.emcdda.europa.eu/system/files/publications/8585/20181816_TDAT18001FRN_PDF.pdf • http://www.emcdda.europa.eu/media-library/infographic-opioid-substitution-treatment-europe-coverage-and-principal-drug-prescribed_en • www.emcdda.europa.eu/data/stats2018/hsr_es 20 Source: www.globalcommissionondrugs.org

We want

a European Union clearly committed against repressive ideology and the criminalisation of drug users and for a policy centred on health, respect for human rights, and fighting against all forms of discrimination and stigmatisation.

We ask the European Union

• **To address in its strategies and action plans on drugs** with the member states:

- **A strong position against the laws criminalising consumption** and for the suppression of imprisonment for consumption and detention for personal use,
- **The implementation of ambitious harm reduction policies both in closed and open settings,** which also take into account the specific needs of women, trans people, people who consume products in a sexual context (Chemsex),
- **To engage stakeholders and civil society** in policy development, implementation and evaluation,

• **The implementation and financing of the seven official recommendations of the EMCCDA[21]**:

- The availability of injection equipment, access to substitution treatment, the screening of infections, and vaccination against hepatitis A and B, access to anti-HIV and anti-HCV treatments, health promotion, universal access to health devices and services,
- **Deployment and widespread availability of medical heroin prescriptions, community delivery of naloxone, safer consumption rooms, reinforcement of education and support for injection, and product analysis,**
- **Strengthening of data collection, health monitoring and research programmes.**

• **To bring a progressive voice on the international scene** calling for the end to the war on drugs and for drug policies to be part of the sustainable development goals and the recommendations of the Pompidou Group[22].

[21] EMCCDA and ECDC, guidance report *Prevention and control of infectious diseases among people who inject drugs*, 2011 [22] Source: www.coe.int/fr/web/pompidou/-/17th-ministerial-conference-closes-with-the-adoption-of-the-stavanger-declaration-

HEALTH IS A RIGHT, UNIVERSAL ACCESS TO MEDICINES A NECESSITY

Demonstration by NGOs against European Patent Policy in front of the European Patent Office, Munich, Germany, September 2018.

Europe is the only WHO region where the number of new HIV infections is increasing. In 2017, 160,000 people were diagnosed to be HIV-positive. And every year, an estimated 112,500 deaths are caused by HCV[23].
The European Union claims a key role in "protecting and improving the health of citizens[24]". Yet, while effective treatments exist, people living with HIV, the hepatitis C virus and/or tuberculosis do not have access to them in Europe.

Barriers prevent access to medicines for all:

• The excessive and arbitrary prices of new medicines that social insurance systems cannot or can barely sustain, preventing patients from accessing the medicines they need,
• The lack of transparency regarding the negotiations around these prices prevents any democratic control, especially in the event of a conflict of interest between state and pharmaceutical negotiators,
• The opacity of the actual amounts invested in research and development even though these investments are advanced by pharmaceutical companies to justify exorbitant prices and that part of the research is made and financed not by them, but by public money,
• A flawed patent system, allowing unjustified monopolies under opaque criteria,
• European directives and regulations protecting the interests of pharmaceutical companies[25], to the detriment of a European framework facilitating access to quality medicines at an acceptable cost.

Misguided patent policy threatens national health systems

The treatments to cure hepatitis C are a perfect example. Upon arrival on the market in 2014, they were protected by the European Patent Office by several patents. This assured monopoly and the price negotiations carried out separately by each State, without visibility regarding the real price paid by the others, gave free rein to a price explosion. This has led to disparities between European countries, where the cure reaches several tens of thousands of euros. Faced with such prices, and while more than 10 million people in Europe are chronic carriers of the virus[26] and have a vital need for treatment, most states have chosen to ration access and to select only some sick individuals for treatment.
Beyond being ethically unacceptable, this situation is undermining public health efforts and jeopardising the survival of our health systems. At a time when the pharmaceutical industry is more profitable than the luxury and petroleum sectors, it is urgent to put an end to this logic of unbridled profits, directly threatening individual and public health in the European Union.

[23] Sources: www.ecdc.europa.eu/sites/portal/files/documents/hiv-aids-surveillance-europe-2018.pdf • http://www.euro.who.int/__data/assets/pdf_file/0009/377253/fact-sheet-hepatitis-c-eng.pdf?ua=1 [24] European Commission website, Health Policy page: www.ec.europa.eu/health/policies/overview_en [25] For example Regulation (EC) no. 469/2009 on the supplementary protection certificate and Directive (EU) 2016/943 on business secrecy [26] World Health Organisation, *Global report on hepatitis*, 2017: www.who.int/hepatitis/publications/global-hepatitis-report2017-executive-summary/en

We want

a European Union guaranteeing universal access to treatment and appropriate prevention tools, for all populations and in all the member states of the European Union.

We ask the European Union

• **To demand the transparency of pharmaceutical companies and states regarding negotiations** on the price of medicines, as well as the money invested in research and development (including public money) in order to set fair and affordable prices,

• **To clean up today's misguided patent system** by making the patent criteria for real innovations more stringent,

• **To revise European provisions** (e.g. supplementary protection certificates, data exclusivity) which extend **monopoly periods** to allow generics onto the market in a timely manner,

• **To support even more European public research** on therapeutic innovations and ensure that the results obtained also remain public, so as not to leave the research and the resulting innovations in the hands of profit-driven pharmaceutical companies,

• **To take into account the voice of the patients and their participation in the whole medicine cycle** (i.e. the governance of clinical trials, the evaluation and negotiation of medicines, etc.), **to avoid the exclusive control of the pharmaceutical industry,**

• **To develop a European strategy** for the supply of health products to avoid stock-outs of essential drugs,

• **To encourage European approaches, such as those of BeNeLuxA[27],** joint purchasing, collaboration and joining forces of member states to negotiate affordable prices with pharmaceutical companies.

[27] BeNeLuxA is a collaboration between Belgium, the Netherlands, the Grand Duchy of Luxembourg, Austria and Ireland, sharing information, expertise and negotiating powers to obtain better prices, price transparency and agreements. More information on the website: www.beneluxa.org


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