

**HUMANITARIAN ALTERNATIVES****HIV/AIDS: may our struggle not become undetectable**

*Florence Thune • Directrice générale de Sidaction*

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Despite scientific research, nearly 800,000 people still die from HIV and 1.7 million others are newly infected each year across the world. Allocating financial resources to this struggle is therefore still a need, as the challenge is to maintain more than 37 million people in care throughout their lives. But because HIV infection is also a powerful indicator of inequality, the response to it must revolve around new alliances between NGOs to pursue a highly political fight.

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**T**hirty-six years ago, in 1983, a team of French researchers discovered the AIDS virus, the human immunodeficiency virus (HIV) that has caused the death of 32 million people and infected 75 million others since the onset of the epidemic<sup>1</sup>. An HIV infection inevitably led to a fatal outcome in the absence of effective treatment, but things changed from 1996 onwards with the advent of antiretroviral tri-drug therapy. For patients who could be treated and withstand its adverse side effects, this was a revolution: one no longer died of AIDS, but could live with the virus more or less satisfactorily with a daily intake of antiretroviral drugs for the rest of one's life.

These drugs, like all those that effectively treat different diseases over the course of several years, are, of course, available only in high-income countries. But a powerful, sweeping movement, spearheaded by people living with HIV everywhere on all five continents, began grappling with the issue of making antiretroviral treatment financially affordable, and in doing so changed the lives of millions of patients around the world.

**The power behind a community**

This movement, supported by the humanitarian and scientific research community, waged a battle to make antiretroviral drugs widely available and affordable, particularly in Africa where 70% of the world's HIV-infected people live. This battle was fought with staunch international advocacy and a formidable legal arsenal, like the one that, in 2001, succeeded in having 39 pharmaceutical industries acquiesce to Treatment Action Campaign, a leading South African association, and to Médecins Sans Frontières. This latter victory, thanks to unprecedented international support and technical expertise built over time, was secured through the application of a law enacted in 1997 authorizing the government of South Africa, a country where HIV-infected people have died in the hundreds of thousands, to manufacture and import ARV drugs at a minimal cost, and to expand the access to generics.

In that same year, in 2001, one day before the UN General Assembly, the director of USAID argued that Africans, lacking timepieces, would be unable to follow any type of strict treatment schedule. Fortunately, international and political circles believed that it was then time to take

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<sup>1</sup> UNAIDS, Global HIV & AIDS statistics – 2019 fact sheet, <https://www.unaids.org/en/resources/fact-sheet>

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action and deploy ARV drugs to the poorest countries. Under the leadership of Kofi Annan, Secretary General of the United Nations, and Jacques Chirac, who helped create Fonds de Solidarité Thérapeutique in 2001, the Global Fund against AIDS, Tuberculosis and Malaria was created in 2002. Since then, more than 32 million lives have been saved through its programmes funded by donations from sixty countries and from private partners like the Bill and Melinda Gates Foundation. This multilateral funding organisation has directly contributed to lowering the number of deaths from AIDS, tuberculosis, and malaria by 40% since 2002. Often accused of working in seclusion and of being rooted in a pathological approach, the Global Fund has gradually increased its share of funding for the betterment of public health systems with over a billion dollars earmarked annually. In addition to its programmes designed to provide better prevention and treatment against these three diseases, the Global Fund has attracted notice for its attention to groups that have been the most affected by HIV and tuberculosis, mainly drug users, sex workers, and homosexuals, those who have been the most exposed to exclusion and stigmatisation. The Fund promotes human rights, which, if not recognised, impede the provision of health services and of gender-based approaches that give girls and women the opportunity to receive preventive treatment within the scope of their sexual and reproductive health. This issue is all the more crucial when we know that HIV/AIDS remains the leading cause of death in the world among women aged 15 to 44.

### Continuing financial needs

Despite these substantial commitments, unquestionable scientific advances, and the sharp decline in patient mortality, HIV remains a killer. Each year across the world, 770,000 people die and 1.7 million are newly infected, with infections having risen in a number of countries, notably in Eastern Europe. Of the 37.9 million people living with HIV in 2018, just over 23 million had access to treatment.

In the face of this incurable disease that must be monitored for life, global challenges are tremendous. In attempting to achieve Sustainable Development Goal 3 of ensuring “health and wellbeing to all at all times”, and to meet UNAIDS’ 95-95-95 target set for 2030<sup>2</sup>, an additional 10 million people, at least, will need to be treated over the next ten years. In addition, international and national State funding for lifelong ARV treatment to a minimum of 33 million people must be found. At a time when the World Health Organisation has set off alarm bells in the wake of the pockets of disease resistance emerging in twelve countries, rendering some drugs ARV ineffective against the virus<sup>3</sup>, all-out efforts must be stepped up to ensure that the progress in reducing the number of deaths and newly acquired infections will not be impeded.

This issue formed the backdrop of the Global Fund’s Sixth Replenishment conference that was recently held in Lyon on October 9 and 10, whose aim was to raise at least 14 billion US dollars to cover most of the needs<sup>4</sup> of its upcoming 2020-2022 funding cycle. Its goal nearly having been

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<sup>2</sup> To ensure that 95% of people living with HIV know their HIV status, 95 % of people who know their status are on ARV treatment, and 95% of people on treatment have an undetectable viral load, (thus monitoring HIV over the long term and totally avoiding the sexual transmission of HIV).

<sup>3</sup> Emiliano Rodríguez Mega, “Alarming surge in drug-resistant HIV uncovered - The drug-resistant form of the virus has been detected at unacceptable levels across Africa, Asia and the Americas”, Nature, 30 July 2019, <https://www.nature.com/articles/d41586-019-02316-x>

<sup>4</sup> Needs were actually estimated at 18 million dollars in the hope of meeting the objectives set by UNAIDS for 2030. See: “GFAN Statement on the Global Fund Investment Case Announcement”, The Global Fund Advocates Network, 11 January 2019, <https://www.globalfundadvocatesnetwork.org/gfan-response-to-the-investment-case-announcement/>

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reached (80 million dollars still short), this conference is deemed to have been a surprising success given today's difficult task of mobilising governments in the fight against HIV, and despite the many open challenges.

In spite of the billions having been raised as mentioned above, associations and communities, the ever-present stalwarts in the worldwide fight against AIDS, have expressed their concerns. Budget decisions based on a race to meet goals in the fight against AIDS and achieve the 95-95-95 targets obscure the fact that HIV not only causes a medical condition, but also generates a social stigma. There is disquieting apprehension on the rise or reappearance of inequalities, and on processes of exclusion and discrimination that have played into the spread of the HIV epidemic in France and elsewhere throughout the world.

### Continuing apprehension

Whatever the scientific advances may be, and whatever the improvement of health systems may be with the billions that have been injected, these efforts will be futile if people have no access to health care or are rejected, simply because they are LGBTs, drug users, sex workers, prisoners, or immigrants. As long as people have no safe place to discuss their sexuality, as long as they are victims of sex-based violence, as long as governments disclaim their fundamental rights, the epidemic will not abate.

Unfortunately, there is no need to look next door to detect the deleterious effects of policies that do not provide care to people suffering from life hardships. French immigration policies in these last few years have finally put some people in extremely precarious situations, exacerbating their risk of an HIV infection. Let us recall that many sub-Saharan Africans living with HIV in France were in fact infected after having immigrated, as was revealed by the survey conducted by the French Agency for AIDS and Viral Hepatitis Research (ANRS)<sup>5</sup>. And further concerns are being raised as to the fundamental principles of France's health care system being threatened to the point that the health of those concerned could continue to worsen.

More generally speaking, in France and elsewhere, associations are coping with the difficulty of raising money to pay for essential staff who can care for people living with HIV but outside of the strictly confines of the medical sphere. These personnel play a mediating role in overall health conservation, peer health education, maintenance of healthcare regimes, social and legal support, etc. Their fundamental tasks, often entrusted to people from vulnerable communities directly affected by HIV, have made the fight against AIDS in many countries a success.

Available funding nowadays is primarily set aside for HIV testing, for the purchase of antiretroviral drugs, and the payment of medical staff salaries. There is no doubt that rapid serological testing and early treatment are crucial, if any hope can be had to put an end to the HIV epidemic, especially since science has proven that the virus cannot be sexually transmitted by a patient under effective treatment.

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<sup>5</sup> Anne Gosselin, Andrainolo Ravalihasy, Julie Pannetier, France Lert, Annabel Desgrées du Loû, "When and Why? Timing and Determinants of Post-Migration HIV Acquisition among Sub-Saharan Immigrants in France", *Sexually Transmitted Infections*, July 2019, <https://sti.bmj.com/content/early/2019/07/26/sextrans-2019-054080.full>; see the ANRS/IRD press release, « Immigrés : une majorité des infections VIH surviennent dans les 6 premières années de vie en France », [www.anrs.fr/sites/default/files/2018-07/CP%20PARCOURS\\_web.pdf](http://www.anrs.fr/sites/default/files/2018-07/CP%20PARCOURS_web.pdf)

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But health human resources in the world are inadequate to meet the challenges that lie ahead in the fight against AIDS. Additionally, a growing number of people living with HIV will be or are already advancing in age and may need to cope with cardiovascular diseases or cancers related to the ill effects of long-term therapy, or with chronic inflammatory conditions caused by HIV.

To respond to these issues, health systems must of course be strengthened and health services decompartmentalized. In addition, the life experience of the patients themselves, the “expertise” of those who are the most concerned, must be used to advantage, not only for them to manage their own condition, but also to provide support to their fellow patients. The life experience that is shared by a patient, as we all know, leads to a finer understanding of the disease and its treatment, and helps patients comply with drug regimens with a better knowledge of the beneficial effects on their own health, on that of their sexual partners, and on that of their children. This non-medical “expertise” is a factor that can help achieve and maintain overall health.

But this “expertise” must be valued and recognised in payment, just as it is when these patients work in diverse jobs, such as health mediators, communal health workers, psychosocial counsellors, etc. Everywhere in the world, these jobs have made a considerable impact on both disease prevention and the support given to people suffering from chronic conditions, such as HIV infections, diabetes, and many other noncommunicable diseases.

A long winding path lies ahead strewn with pitfalls and buffeted by headwinds before we reach the end of the HIV epidemic tunnel. Advances in scientific research and progress in antiretroviral therapy have rendered the AIDS virus “undetectable”, even though it actually still present. But as we stand before the challenges that await us, what must not become “undetectable” is our struggle against this waging epidemic, our fight for a more egalitarian and less exclusionary universe. For this to happen, for us to become “detectable”, and to lend solid credence to our voice, we must strengthen our NGO alliances, look beyond our own specific actions, and coordinate our common advocacy and our struggles in the political arena. One NGO alliance bore fruit during the recent Global Fund conference with the initiatives carried out in France by a dozen associations and NGOs from various backgrounds. They were wise enough to put aside their self-interests to carry a common banner of political advocacy to the French government. This alliance also upholds the French medical health system through its strong links with the research community, which, in turn, provides scientific evidence that strongly reinforces the well-argued positions of our advocacy. Unless we form alliances and lead forceful political struggles, we will remain relegated as mere spectators of a growingly inegalitarian world.

*Translated from the French by Alan Johnson*

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**Biography • Florence Thune**

After completing her initial studies at l'École Supérieure de Commerce et de Développement, Florence Thune first joined NGO Handicap International (HI, now known as Humanité & Inclusion) in Djibouti in 1987 as an administrator and a finance manager. This marked the launch of her 18 years of collaborative work with the NGO that eventually led her to Thailand, and then to Pakistan and Somaliland as Programme Director. In 1997, she joined the association's headquarters as the Director of the Horn of Africa and Great Lakes Region Programmes, before assuming the position of Assistant Programme Director, during which time

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she led HI's involvement in the fight against HIV. Florence Thune joined Sidaction in May 2005, as Head of the capacity building unit in the international programme department. In 2015, she became the Director of the French programme department before being appointed in 2017 as the association's General Director. Florence Thune has been living with HIV for 23 years and has publicly testified her seropositivity.

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