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Aids

# Vulnerability and resistance

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### Interview with Marc Nectar, president of Act Up Paris.

*When did Act Up come to France?*

**Marc Nectar:** Act Up France was born in 1989, inspired by Act Up New-York, formed two years earlier by the gay writer Eric Rameur. Since then, Act Up Paris has been linked to the momentum of the Gay Pride movement, since here in France AIDS is still an epidemic which mainly affects the gay community (40% of the HIV positive are homosexuals). Our goal is to put pressure on the authorities and the institutions on all questions linked to the epidemic.

Back in 1989, the authorities talked as if "queers and drug addicts" were the only people affected by AIDS. And we were left to sort things out by ourselves. A range of organisations like Aides and Vaincre le Sida were formed, to look after the sick, and fight for better access to health care and against discrimination. Act Up was founded by people who wanted to politicise the AIDS debate. We are not a support group for those with HIV, but a political association. Our strategy is pressuring the powers-that-be using non-violent action and the media.

Act Up has organised a whole series of short actions ("Zappings"), which aim to shock public opinion, and generate the images and reactions which will oblige the media to discuss the problem in the terms set by us. We were determined to stop the pathetic "oh how sad that these poor people are dying so young" treatment the issue was receiving. Our most spectacular action was the December 1993 action at Place de la Concorde. We also played an important role in exposing the scandal over contaminated blood products. At first, the haemophiliac associations were reluctant to link their "innocent" infection with ours. That changed when we were able to explode the whole scandal.

In 1990, Act Up occupied Notre Dame Church, right in the heart of Paris, to denounce the complicity of the religious hierarchy in homophobia, and the Catholic Church's refusal to approve the use of condoms to protect people against this epidemic.

We work in a completely democratic way. We have learned from the mistakes of many of the groups created after May 1968. Particularly the various homosexual organisations, which became nothing more than talking shops. Act Up is a much more structured, disciplined association, with clear responsibilities and a leadership. But also with an open weekly meeting in which all members are encouraged to participate. Over the last seven years, attendance has fluctuated between 50 and 300. But every Tuesday there has been a meeting.

We only have three full-timers, for the technical secretariat. The rest of the work is done in permanent commissions or workshops, which allow members to deepen their understanding of a particular theme, and choose what kind of action they want to take. Act Up is a mainly homosexual association, created in the homosexual community. But this doesn't make us the mirror of a ghetto. There is no ghetto, except in some peoples' heads. Act Up is sensitive to all the marginal communities: drug users, immigrants, prisoners and so on.

Take prisoners. The prison protests and strikes of the 1970s led to little change, because no-one in society really supported the prisoners. Today, Act Up is ready to use its energy and its prestige to relay prisoners' concerns, and help find solutions to some of their problems. Act Up will help communities which the state ignores completely.

Act Up challenges a number of established ideas. Notably the nature of scientific power. AIDS emerged at a time when science seemed able to solve all our problems, and society looked forward to total mastery over our environment. AIDS changed all that. Science found itself helpless, confronted with a new, mutant virus and a new epidemic. 16 years later, science has still not fully understood the mechanisms of AIDS. This challenges the legitimacy of the scientific and medical establishment.

In the first decade of AIDS, doctors knew no more than their patients. Indeed, it was often the patients who taught the doctors about HIV, and the various treatments being developed, particularly in the USA. The patients gained a real power which, today, is being extended to other pathologies. This is profoundly modifying the relationship between doctor and patient, though of course the process is still fragile and embryonic. The patient is more and more a partner in the healing process, an associate in the treatment programme, and no longer just "patient" in the sense of calmly waiting for a more powerful party to decide to act.

AIDS hasn't just changed this in philosophical terms, but in research practice too. AIDS is the only pathology where the patients are linked to the research process on a daily basis, in France through the National AIDS Research Agency (Agence nationale de recherche contre le Sida). In the USA too, no new treatment is applied without the agreement of the patient. Nor is any new treatment put on the market without the agreement of the associations of HIV sufferers.

Act Up has shown that we can make the authorities take our concerns into consideration, and modify their behaviour.

*The new "tritherapy" (combination of drugs) has led some experts to claim that the epidemic is under control?*

Therapeutically, things changed considerably in 1996. We are in a new, uncertain phase. One year ago, the US Congress suggested a new treatment, combining "antiproteases" operating on different parts of the virus, in different ways. It seems that, in combination with existing treatments for HIV, this new therapy in many cases improves the health of HIV+ people considerably, allowing them to regain strength, and, of course, to live longer.

The media and public opinion have embraced the antiproteases news very enthusiastically, and are crying "victory!" a little too soon. Act Up recognises the importance of antiproteases, and the improvements they seem to have brought. But we are also concerned about problems of resistance to this new treatment. Clearly the new treatment is unsuitable for some patients. So we still need a range of treatments to become available, to compensate for those which, tomorrow or the day after, may prove to be ineffective.

There is a risk that people will become less militant because of this new treatment, even though many questions are still not solved. Issues like access to treatment, the social security provision for HIV+ people in marginal situations, HIV+ prisoners, the lack of social recognition for homosexuality, the pressing need to de-criminalise drug use, and begin helping drug addicts.

If the public really begins to think that the epidemic is over, we will find it much more difficult to continue our mobilisation, and to deal with a number of social questions which are at the very heart of the AIDS crisis.

The central issue for me today is vulnerability. Contamination happens where there is vulnerability. If we don't understand this vulnerability, we can't explain why, despite the prevention campaigns, despite the fact that most people know that you must use a condom or a clean needle if you take risks, the number of new infections has hardly dropped in the last 12 months. There were 4,796 new cases of HIV in 1996, only 300 less than in 1995.

No "superdrug" therapy will solve the AIDS crisis, until we deal with this vulnerability, with the fact that individuals and social groups are vulnerable to infection. Homosexuals are vulnerable because it is hard, in France and elsewhere, to admit to being homosexual. Drug users continue to get sick because they are seen as criminals, rather than people who suffer. In Africa, women are more vulnerable to AIDS because they lack weight in society.

*What does Act Up say about drug use?*

The central question is this: why are drug users 30% of the HIV+ population? If so many drug users are contaminated, it is surely because we have a juridical framework which defines drug use as crime and drug users as criminals. As a result, drug use can only be secret. Within this secret world, little attention is paid to public health messages from outside. And only since 1995, 15 years after the epidemic began, have French NGOs been allowed to distribute clean needles to drug users.

For years now, Act Up has been arguing for the installation of automatic syringe distributors in the appropriate locations. Local politicians avoid making the decision, for fear of upsetting their reactionary voters. There is only one public syringe exchange/distribution machine in the whole of Paris! The only town which has made a real effort (eight machines) is Marseilles, which has a right wing mayor.

Act Up proposes:

- the abolition of the 1970 law criminalising drug use, and the introduction of a real prevention policy, directly addressed at drug addicts, and recognising these people are fully responsible adults, not children or criminals. Let's stop thinking that public health materials about dirty needles has to be like a comic strip!
- improving drug addicts' access to health care. The special health services created for drug users are certainly useful, but why are they less well funded and equipped than the rest of the health service?
- challenging the Ministry of Health's authoritarian substitution programme. The Ministry tries to bring drug addicts "back into line," using AIDS as a means of controlling addicts, by providing tranquilliser products. These substitutes could be much improved. Act Up demands that a range of products, and substitution methods be made available, covering the whole range of drug products actually in use.
- the distribution of heroine, under medical supervision. For some drug addicts, this is the only solution. France is behind a number of other countries. Even Margaret Thatcher approved a more pragmatic policy.

*The new tri-therapy will never be commercialised in the third world...*

On World AIDS Day, 1st December 1996, you could see that the media, the authorities, the voluntary sector and public opinion are less concerned about AIDS than they used to be. People are saying, more or less, that the epidemic is over in the northern countries, and that the only big problems are in the south.

This very "politically correct" discourse usually urges us to do more for HIV patients in the third world, who represent 95% of all sufferers. In reality, AIDS is no more a priority in the south than in the north. The French Ministry of [foreign] Co-operation recently decided to stop prioritising the struggle against AIDS in its African programmes. Why? Above all because of lobbying from the right-wing within the governing coalition(not even the far right). These politicians want France to prioritise aid to obstetrics and maternal care, rather than AIDS as such. Obviously, these are important questions,since there are many HIV infections from mother to child.

But the new orientation is based on side-tracking AIDS. Same pattern in the north. The most reactionary parts of the right are trying to stop the public health system from talking about AIDS even here.

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Why the shift? Quite simply because these new therapy rely on administering several expensive drugs in combination. No country, no aid programme official wants to admit that sufferers in the south will never receive the most effective treatments which have been developed in the north, and that the North will never make the necessary huge funds available to introduce treatments like AZT in the South.

The only remaining solution is to de-prioritise AIDS. If public opinion pressure fades, the embarrassing question of why these treatments are not available in the South will not have to be faced in the same way.

At Act Up we say that "the priority is everywhere, or it is nowhere!" When one tries to de-prioritise AIDS in public health programmes in the North, part of the reason is to solve base financial questions in the South. This is scandalous and criminal. We must keep shouting out: "the AIDS epidemic isn't over!"

*Interviewed for International Viewpoint by Sonia Leith. Previously published as "On nous parle d'espoir!", Inprecor #410.*