



Nothing for us without us !

From community-based principles
to health democracy:

**How AIDS activists have created their own place
in the French health care system**

70's : The beginning



- The concept of patients' representation takes place in the larger framework of patients' rights
- In the 70s, the state started to acknowledge the rights of patients to consent to treatment
- 1974: 1st charter of hospitalized patients

And then came AIDS...



- The lack of a medical solution to prevent death in the AIDS field changed the relationship between doctors and patients
- 1983: Denver statement : “We are people living with HIV/AIDS, we struggle for life”.
- PLWHA demand to be included in every kind of decision and have their experiences acknowledged

... and patients' voice emerged



- In 1984, Daniel Defert created AIDES, the 1st French HIV CBO
- Based on community involvement
- Concrete action provides material for advocacy
- Experience = knowledge. The objective is to change society
- 1992 : PLWHA representatives started to participate in **ANRS**' work

The G.I.P.A principle



- GIPA = Greater Involvement of People living with HIV & AIDS
- Adopted in Paris in 1994 by 42 countries
- The Joint United Nations Programme on HIV and AIDS (UNAIDS) has promoted GIPA since its beginning by involving people living with HIV at all levels

1995-2004 : the legal issue



3 key-dates:

- 1996: « Juppe statement »
- 1998-99: Health convention organised by the authorities
- 2002: 4th March law relative to patients' rights and quality of the health care system

Representation, but in conditions...



- NGOs and individuals have to meet conditions to represent patients
- Every representative has to be a member of a registered NGO
- The agreement is delivered by a national commission

The example of COREVIH



COREVIH: Regional Coordination for HIV/AIDS Healthcare

Their aim is to improve the quality of comprehensive care of PLWHA independently of hospitals

In the fields of:

- Care
- Support
- Research
- Prevention & Testing



VOTERIEZ-VOUS POUR MOI SI J'ÉTAIS SÉROPOSITIF ?
C'EST LE SIDA QU'IL FAUT EXCLURE, PAS LES SÉROPOSITIFS.

