

# Role of the HIV/AIDS community in science & advocacy

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European AIDS Treatment Group  
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# Informed Patient/Advocate

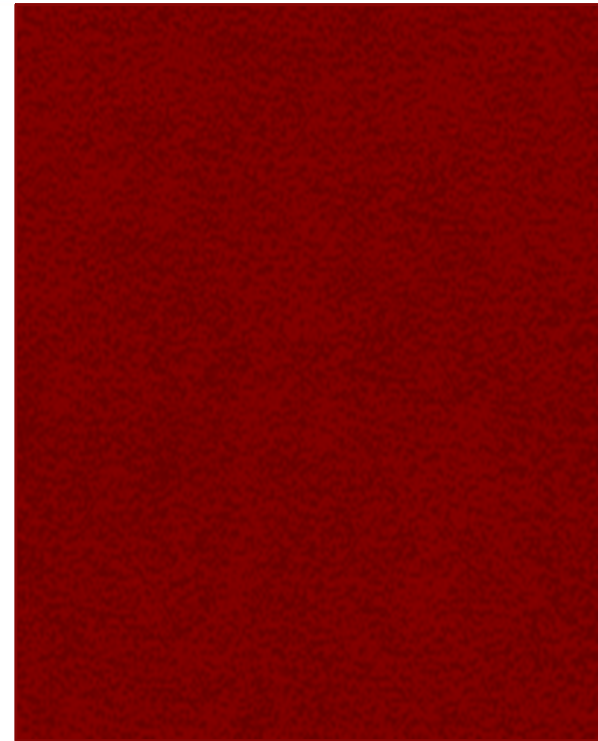
- Treatment information & Co decision about personal health
- From scrutiny of public money on research, to grants review
- Monitoring and participation in Drug development and clinical research
- Members of Scientific Committees, CABs and Guideline Panels
- Experts and members at Regulatory Authorities
- Heads of major research focused organisations
- International Organisations (WHO, UNAIDS, Global Fund, UNITAID, Medicines Patent Pool)
- National Strategy and Programs







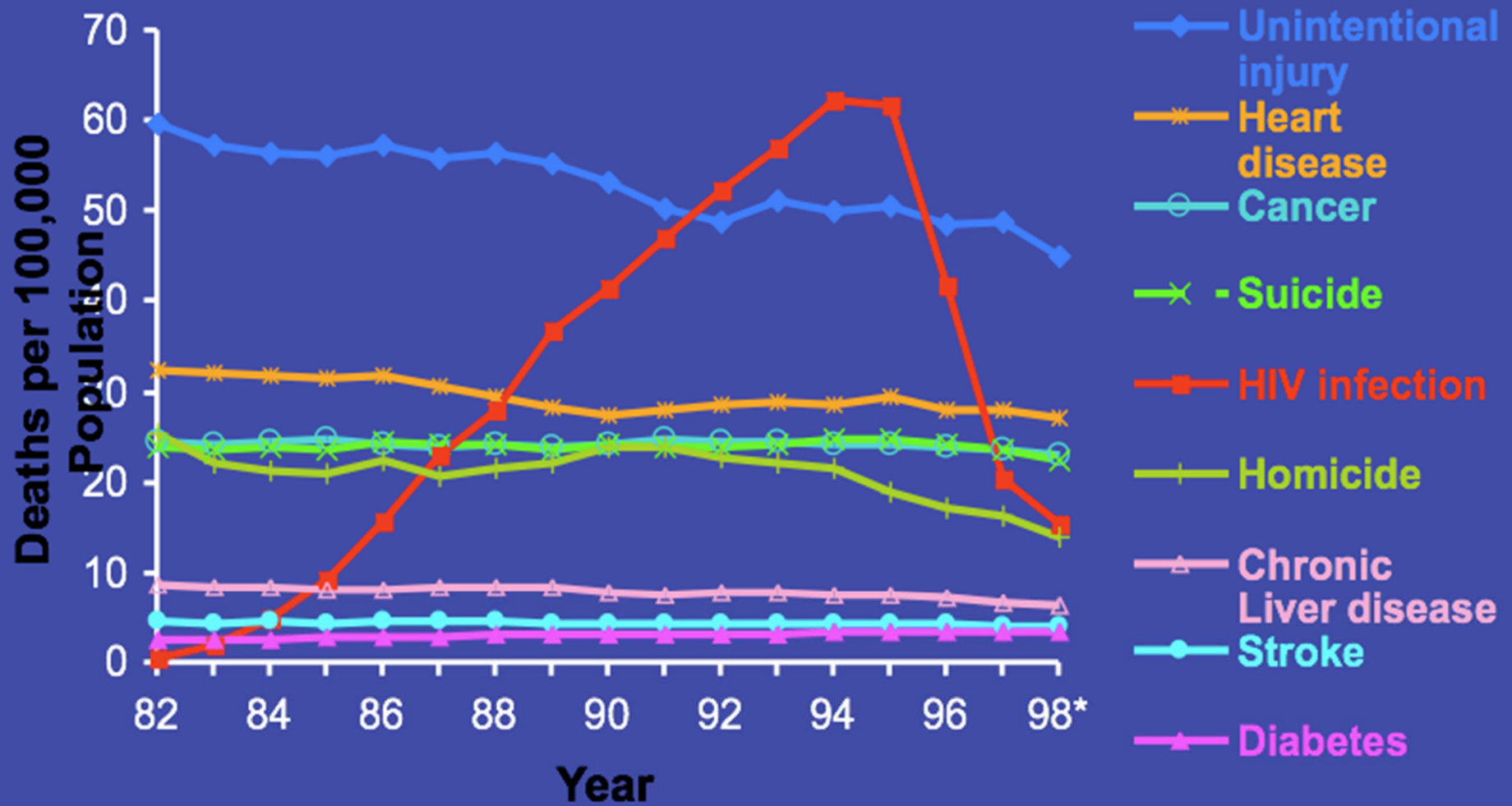




**Haitian Patient, before and after Receiving Free Treatment for HIV Infection and Tuberculosis.**

The photograph on the left was taken in March 2003, and that on the right in September 2003. Many impoverished patients in rural Haiti and Rwanda now receive comprehensive medical care through public-private partnerships.

## Causes of Death for men 25-44 in the USA 1982-1998





# The 80s....



# Denver Declaration (1983)

## “Nothing about Us, Without Us”

We condemn attempts to label us as “victims”, which implies defeat, and we are only occasionally “patients”, which implies passivity, helplessness and dependence upon the care of others. We are “people with AIDS”



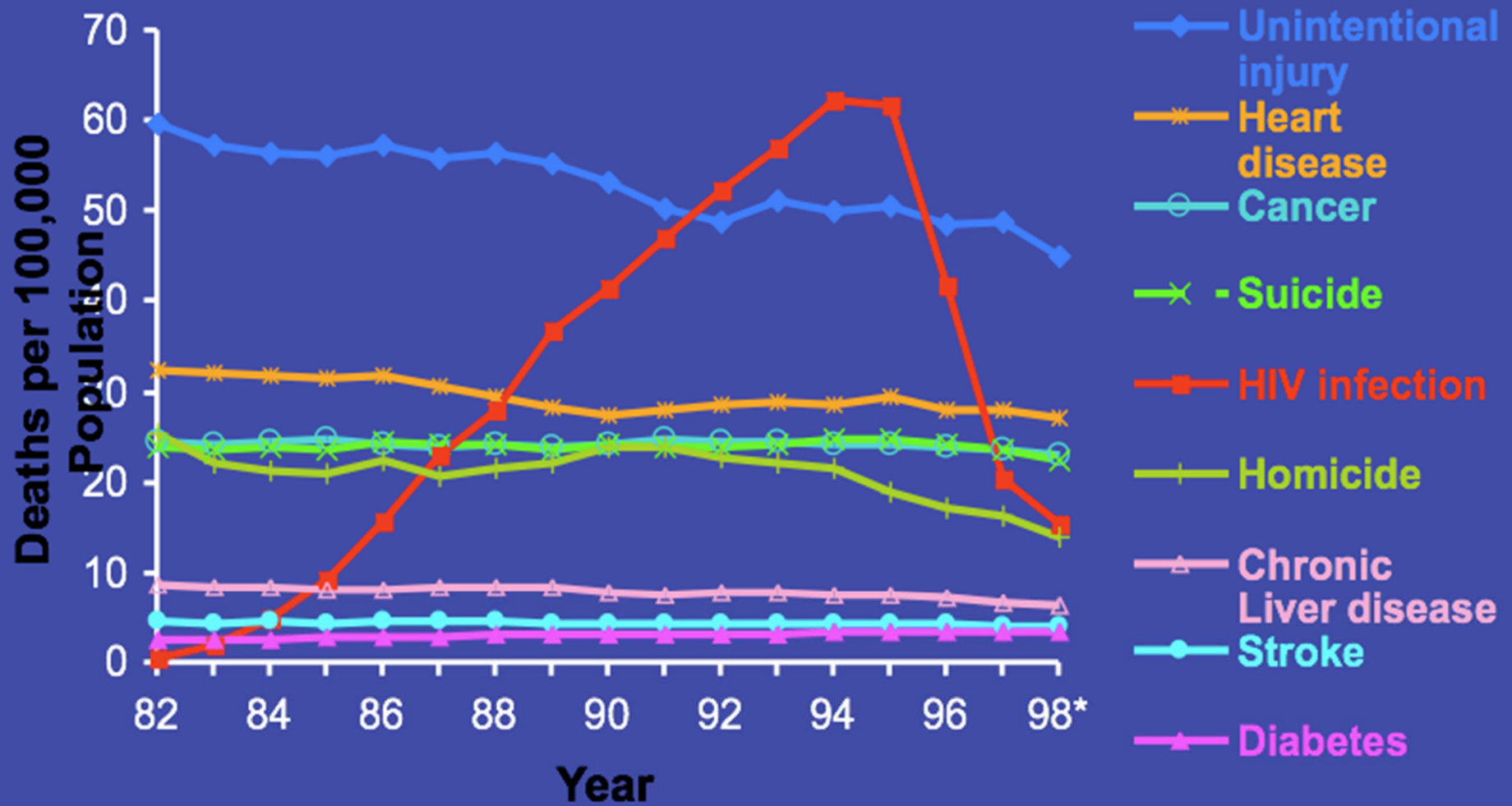
# Denver Declaration (1983)

“Nothing about Us, Without Us”

We recommend that people with AIDS:

- 2 Be involved at every level of AIDS decision-making and specifically
- 3 Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge

## Causes of Death for men 25-44 in the USA 1982-1998





# FDA-Approved Antiretroviral Drugs

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## NRTI

- Zidovudine
- Didanosine
- Zalcitabine
- Stavudine
- Lamivudine
- Abacavir
- Tenofovir
- Emtricitabine

## NNRTI

- Nevirapine
- Delavirdine
- Efavirenz
- Etravirine
- Rilpivirine

## PI

- Saquinavir
- Ritonavir
- Indinavir
- Nelfinavir
- Amprenavir
- Lopinavir
- Atazanavir
- Fosamprenavir
- Tipranavir
- Darunavir

## Fusion Inhibitor

- Enfuvirtide (T-20)

## Entry Inhibitor

- Maraviroc

## Integrase Inhibitor

- Raltegravir

## Combinations

- 6 available, combining 2 or 3 drugs



# Impact of ARVs

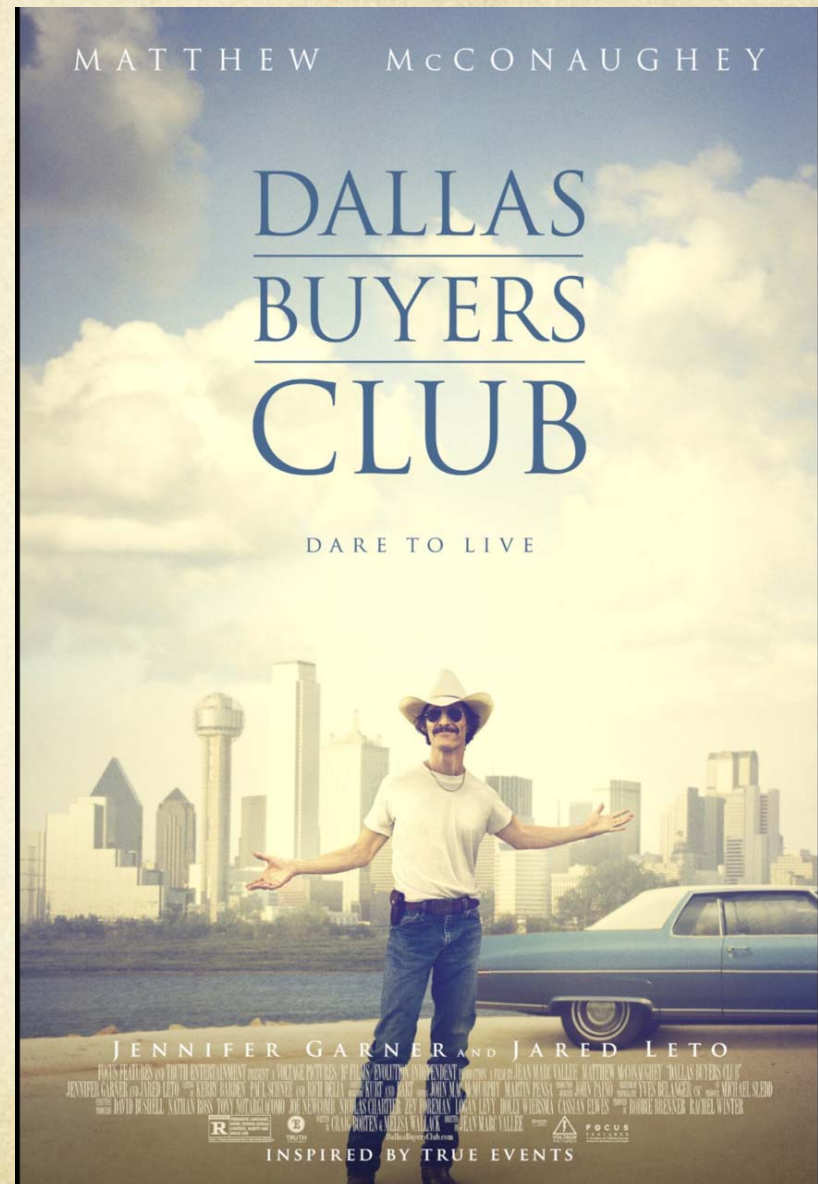


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○ Dallas Buyers Club  
a film by Jean-Marc Valle

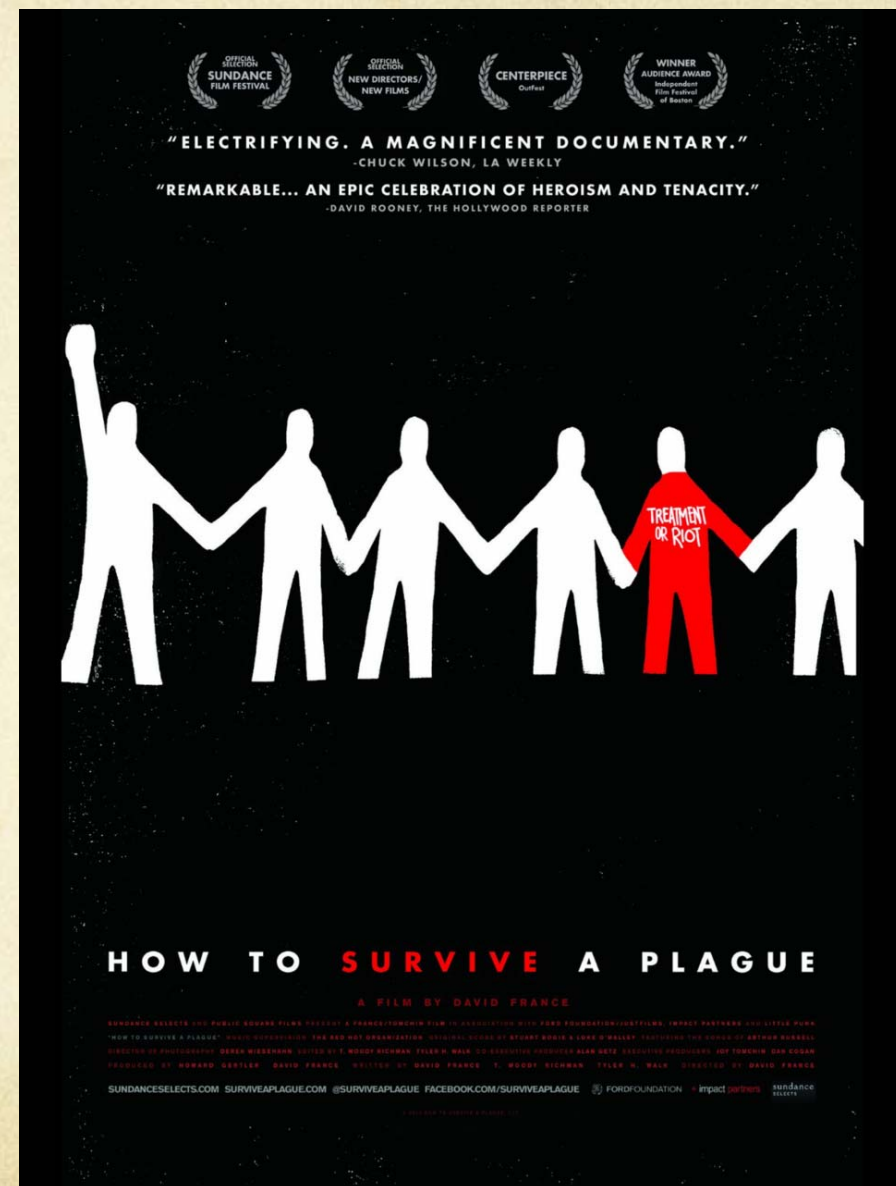


# Community mobilisation





○ How to Survive a Plague  
a film by David France

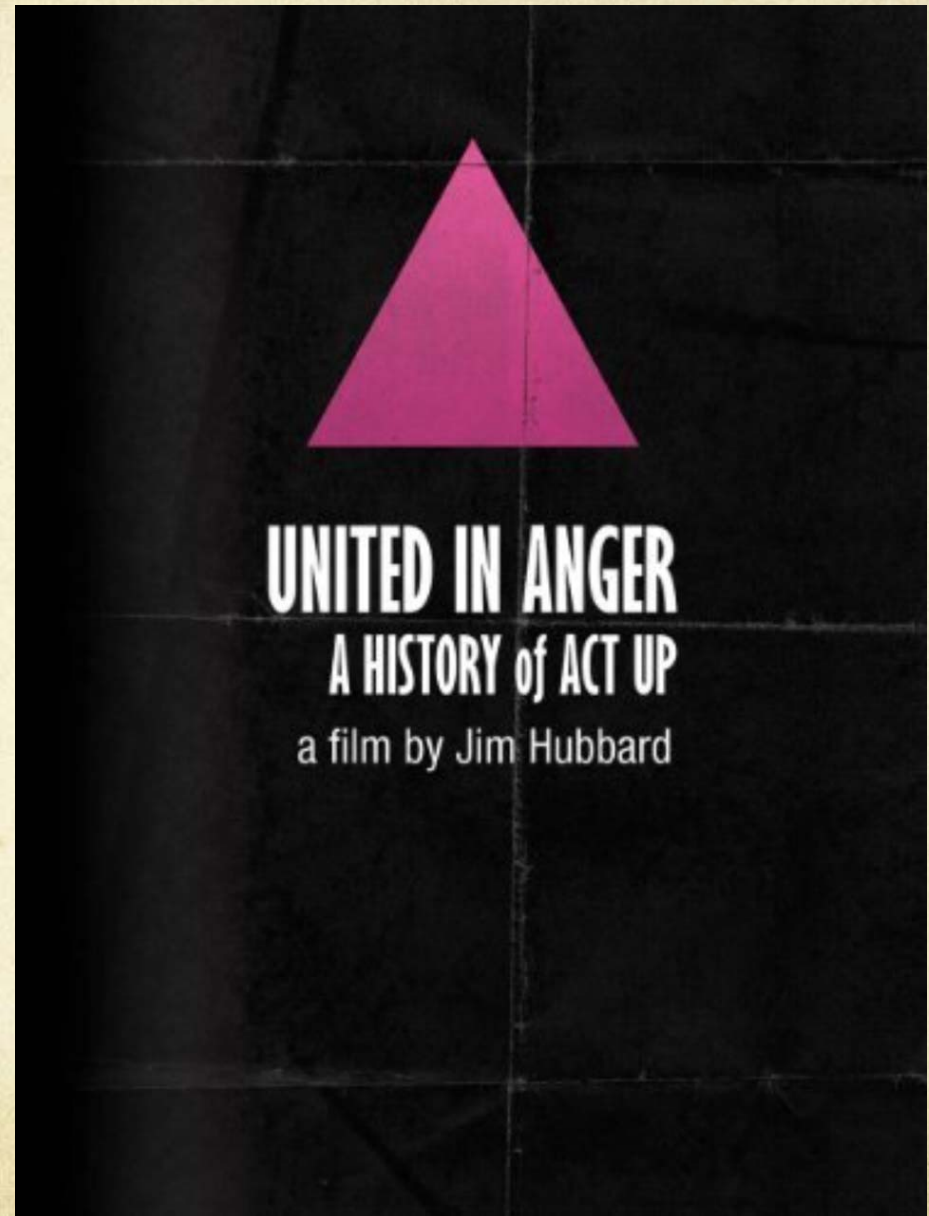


# ACT UP





- A History of ACT UP  
a film by Jim Hubbard



# 1988 FDA demo



Act Up members block the entrance to the Food and Drug Administration building, October, 1988.

Photo © Ben Thornberry



# 1990 NIH demo



# CABs – Community Advisory Boards

- Adult AIDS Clinical Trials Group (AACTG)
- Community Programs for Clinical Research on AIDS (CPCRA)
- Pediatric AIDS Clinical Trials Group (PACTG)
- HIV Prevention Trials Network (HPTN)
- HIV Vaccine Trials Network (HVTN)
- Medical Research Council (MRC)
- Agence Nationale de Recherche sur le Sida (ANRS)
- Numerous industry led – (drug or trial specific)



# EATG (European AIDS Treatment Group)

- Founded in 1992
  - 150+ members from 45 countries involved in local NGOs and related to 30+ networks
- Mission
  - Ensure fastest possible access to state of the art medical products or devices and diagnostic tests that can contribute to the prevention or treatment of HIV and related diseases
- Fields of activities
  - Treatment information
  - Training and capacity building
  - Drug development and clinical research
  - Policy / Advocacy

# ECAB – November 1997 (European Community Advisory Board)

- to advise the research community on the needs of the patient community and the appropriateness of proposed research
- to advise the community on the aims and expectations of a research proposal and the appropriateness of the research



# Trainings & Lectures

- Good Clinical Practice
- Statistics
- Immunology
- Pharmacology
- Virology
- Hepatitis co-infection
- Pharmacovigilance
- Reproductive health
- Clinical Trial's design
- Evidence based medicine
- Clinical Trials Networks
- Cohorts
- EMA – Regulatory authorities
- Pharmacoeconomics - Health Economics
- Prevention Research
- Media Relations

# 2007 (updated 2011)





2010

*The* NEW ENGLAND  
JOURNAL *of* MEDICINE

ESTABLISHED IN 1812

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VOL. 363 NO. 27

Preexposure Chemoprophylaxis for HIV Prevention  
in Men Who Have Sex with Men

METHODS

**PROTOCOL DEVELOPMENT**

We developed the concept and protocol for this study using methods that came to be approved as “good participatory practices” by UNAIDS and AVAC.<sup>18</sup> The development of the protocol

# New Paradigm for Involvement

- Drug & Clinical Research
- Social Sciences
- Implementation Science
- Cure research
- Epidemiology & Disease burden
- Evidence based Policy



# Women's Vote

○ Germany	1918
○ France	1944
○ Switzerland	1971
○ Iraq	1980
○ Lichtenstein	1984
○ United Arab Emirates	2006
○ Vatican	////

# Acknowledgments

- Carlton Hogan†
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- Matt Sharp
- Kevin Fisher