Celebrating 40 years of HIV advocacy: Global action towards improved care, quality of life, and empowerment of people living and aging with HIV

Nikos Dedes
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DISCLOSURES/CONFLICT OF INTEREST

Gilead  Advisory Board, Speaker
ViiV    Advisory Board
GSK     Advisory Board
MSD     Advisory Board, Speaker
RARE CANCER SEEN IN 41 HOMOSEXUALS

Outbreak Occurs Among Men in New York and California — 3 Died Inside 2 Years

BY LAWRENCE K. ALTAN

Doctors in New York and California have diagnosed rare homosexual men with cancer of the rectum from rapidly fatal tumors. Eight of the victims died within two weeks after the diagnosis.

The cause of the outbreak is unknown, and there is no evidence of contagion. But the doctors who have made the diagnosis, most of them in New York City and the San Francisco Bay area, are advising some physicians who treat large numbers of homosexual men to the problem in an effort to help identify more cases and to prevent the deadly disease.

The name of the disease has not yet been officially announced. But the disease, which is called Kaposi's sarcoma, has prompted a medical investigation that suggests it could have a scientific and public health importance because of what it may teach about determining the causes of more common types of cancer.

First Appearance in Spain

Doctors have been taught in the past that the cancer usually appeared first in Spain in the legs and that the disease took a slow course of up to 10 years. But these recent cases have shown that it appears first in the rectum and that it spreads rapidly, often killing the patient anywhere on the body. The cancer generally does not reach the other organs, often can metastasize for decades, sometimes appear on lungs and sometimes even on tonsils and scar tissue after a period of time. The cancer often causes weight loss, shortness of breath, and other symptoms.
The 80s....
1st Milestone – 4 January 1982 - GMHC
SAFE(ER) SEX

Jack Off Party’s

In the mid-1980s, the jack-off parties that Amsterdam Jocks organised in gay bar De Spijker were popular. Men were allowed to kiss, touch and jerk each other off, but no fucking or cock sucking was allowed.
How to Have Sex in an Epidemic: One Approach

By Richard Berkovich
February 24, 1983

*Any element that is added to a metaphor and newly enough-faceted, will be felt to be morally, if not literally contagious.*

—from Henry James, *Illness as Metaphor*
“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”

We recommend that people with AIDS:

Be involved at every level of AIDS decision-making and specifically

Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge
4th Milestone – Community Mobilisation - ACT UP 1987
Tony Fauci

Washington Post
From March to September 2003

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.
Antiretrovirals

Antiretroviral therapy for HIV infection

In the 1990s

Up to 20 pills daily, taken at different intervals throughout the day

Today

As little as 1 pill per day, delivering multiple drugs

#35YearsOfAIDS
IGNORANCE = FEAR

Keith Haring - 1989
THE END story of a three-year struggle against AIDS and its cruellest enemy, David King could light no longer. As his father, sister and friends stood by in anguish, the 32-year-old husband, and brother of five, was engulfed. After five years of pain and agony, the AIDS Foundation felt his life draining away. David whispered, "I'm ready."

took a last, pained breath, then succumbed.
Report on a workshop on Community Advisory Boards

sponsored by the Immuno AG Community Advisory Board

in Bergen, Norway, April 11 - 13, 1997
David France – 2012 (Book 2016)

How to Survive a Plague
The Story of How Activists and Scientists Tamed AIDS
David France
Glasgow Manifesto - 2022

The Glasgow Manifesto
International Coalition of Older People with HIV (ICOPO-HIV)
Proportion of respondents who have ever told people in their life about their HIV status

- **Friends**: 19% None, 30% One or two, 22% Several, 25% Majority, 25% All, 45% Not applicable
- **Family members**: 23% None, 15% One or two, 26% Several, 35% Majority, 24% Not applicable
- **Current sexual partners**: 12% None, 28% One or two, 15% Several, 19% Majority, 12% All, 4% Not applicable
- **Previous sexual partners**: 18% None, 13% One or two, 15% Several, 10% Majority, 6% All, 4% Not applicable
- **Co-workers**: 5% None, 12% One or two, 21% Several, 24% Majority, 4% All, 5% Not applicable
- **Other people (e.g. neighbours)**: 4% None, 4% One or two, 12% Several, 12% Majority, 4% All, 5% Not applicable

Criminalization of Clients in France - 2016
ILGA - Rainbow Map 2022
We have to abandon liberal methods and principles of organizing a society.

Viktor Orban