



European
AIDS Treatment
Group

EATG's Interactions & Collaborations


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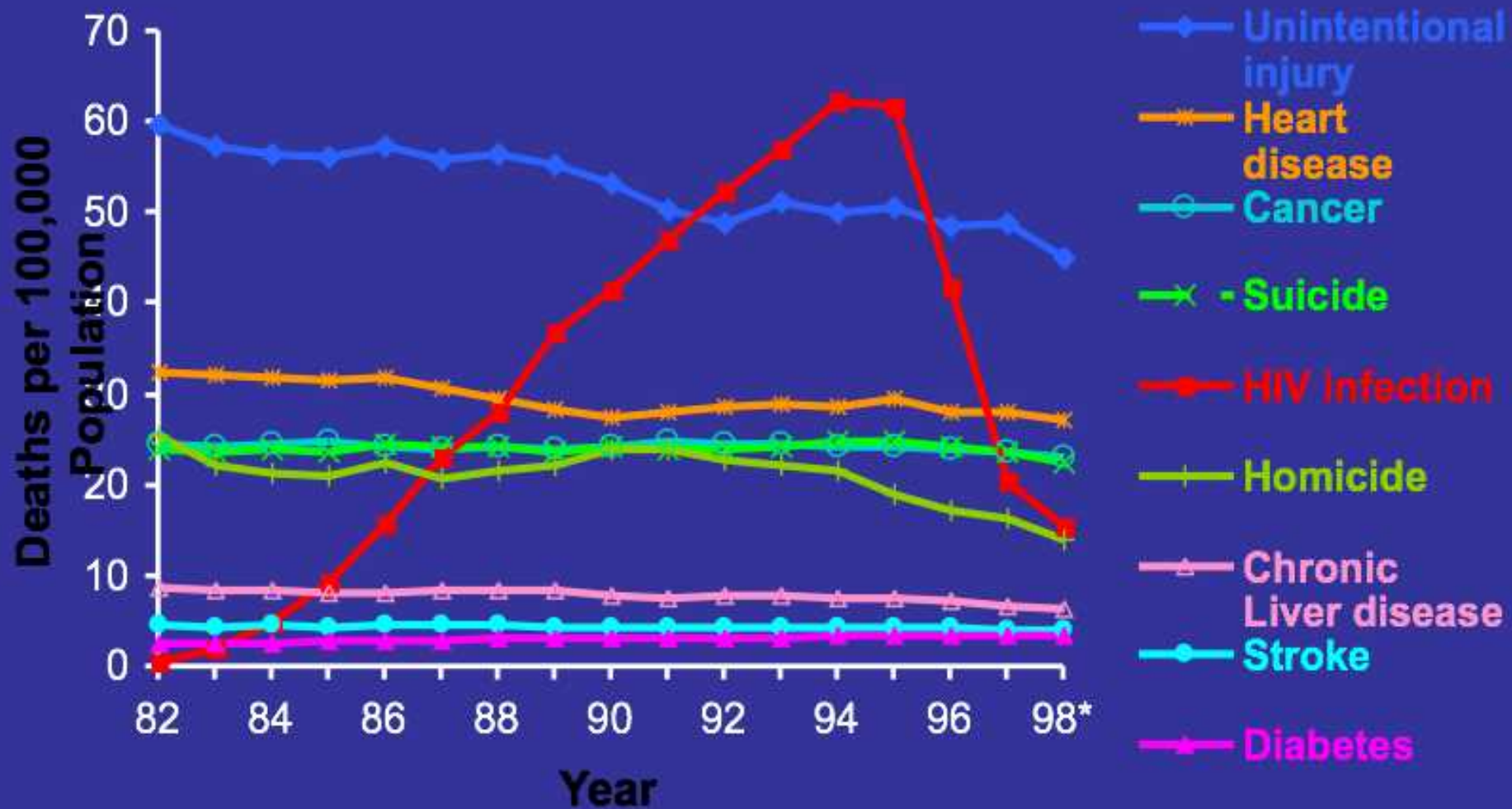
EATG

- Founded in 1992, based on need for single voice of people living with HIV in Europe
- Mission > Ensure fastest possible access to state of the art medical products, devices, diagnostics and prevention
- Today, 117 members from 43 countries in Europe involved in the fight against HIV, TB & Hepatitis

Main activities

- Capacity building: treatment literacy training and Treatment Information
 - Interaction with Drug Development and Clinical Research
 - Policy / Advocacy
- 

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



FDA-Approved Antiretroviral Drugs

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





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.

Civil Society mobilisation



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

1988 FDA demo



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

Photo © Ben Thornberry

1990 NIH demo



Model of interaction

Ongoing platform for dialogue between PLHIV/their advocates, clinicians, researchers, research consortia, health agencies, pharmaceutical companies, and policy influencers

- Meetings (with specific themes) and follow-up communication
- Active involvement in scientific and regulatory fora (representation)

Commission

- DG Sanco
 - EAHC
 - Health Policy Forum
 - Think Tank
 - Civil Society Forums (HIV, Sexual Health)
- DG Research
 - Reviewers
 - Research priorities
 - Advisory meetings
 - Projects (NoE, Cohorts)

European Parliament

- Questions to Commission & Council
- Resolutions & Declarations
- Informal Groups like MEPs Against Cancer (MAC)
- Environment, Public Health and Food Safety Committee

EU Bodies & Agencies

- European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) 1993
- European Medicines Agency (EMA) 1995
- European Ombudsman 1995
- European Centre for Disease Prevention and Control (ECDC) 2005
- Executive Agency for Health and Consumers (EAHC) 2005
- European Union Agency for Human Rights (FRA) 2007

European Medicines Agency

- Participation on Management Board
- Committees
 - Medicinal Products for Humans
 - Orphan Medicinal Products
 - Paediatric Committee
 - Advanced Therapies
- Patients' and Consumers' Working Party
- Pharmacovigilance
- SAGs
- Ad Hoc Groups

ECDC

- Advisory Forum
- Memorandum of Understanding with the EU HIV/AIDS Civil Society Forum
 - Workplan
 - Consultations
 - Advisory boards

WHO Euro

- Based in Copenhagen
- Region of 53 countries
- Innovative initiative in 2005 to engage with POs
- Memorandum of Understanding with EATG, 2005
- Consultations
- Guidelines

Interactions

- Scientific Societies
 - Conferences
 - Guidelines
 - Trainings
- Research Agencies
- Public Health Forums
 - Gastein
- Industry
 - Drug Development
 - Advisory Boards
- Health Technology Assessment Agencies

Participation to organisations & networks

- EFGCP (WG)
- EPPOSI (BoD)
- EPHA (BoD)
- IAPO (BoD)
- AIDS & Mobility
- EHRN
- ITPCru
- ECUO
- AAE (BoD)
- Correlation
- EPF

ECAB Activities

Discussions around:

- Influencing content and design of clinical trials and protocols
- Research, and other strategic programmes (e.g compassionate use, Cure, TASP)
- Training (on specific topics)
- Increasingly involved with co-morbidities: (Hepatitis C, TB etc.)

ECAB: Representations

- EMA PCWP (co-chairing) & Paediatric Committee
- DSMB (several)
- ECRIN
- Drug Interactions Website (Liverpool)
- FCHR (Washington)
- HIV Drug Therapy Congress (Glasgow)
- EACS Conference
- Stop TB Partnership
- NEAT
- PENTA
- CHAIN
- COHERE
- CHAARM
- EuroCoord

Information Age

The period beginning around 1970 and noted for the abundant publication, consumption, and manipulation of information, especially by computers and computer networks

***Corporate* State**

- Control
- Law
- Regulation
- Self regulation

Citizen

- Informed
- Engaged
- Consulted
- Involved
- Control

EA Europe
DECEMBER 25, 2006 - JANUARY 1, 2007
www.time.com

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Patient Organisations

- Increased in number and influence
- Large differences between old and new Member States
- From paternalism to empowerment
- Care - education - support → Advocacy
- Internet - Networking - Community building
- EU Institutions - European POs
- Health Policy - Beyond specific diseases

Role of Patient Organisations

- Treatment information and disease management
- Involvement in Drug Development & Clinical Trials
- Increased institutional involvement in Regulatory agencies
- Scientific Societies
- Advocates with payers and HTA agencies
- Pharmacovigilance

Credibility & Influence

- Create capacity on national, regional and international level
 - Educate yourselves on all topics – Become experts
 - Create a community
 - Network with fellow patients
 - Knock on all doors
- 

Informed HIV Patient / Advocate

- Co decision about personal health
- Scrutiny of Public money on Research
- Monitoring and Participation in Drug Development
- Member of Scientific Committees and Guidelines
- Part of National AIDS Coordinating Authorities
- Recognised experts at Regulatory Authorities

Women's Vote

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

THANK YOU!

