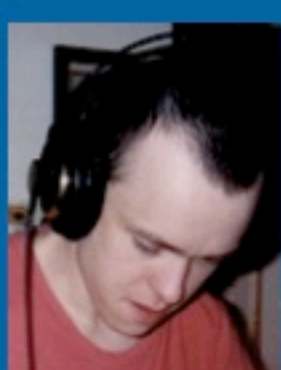
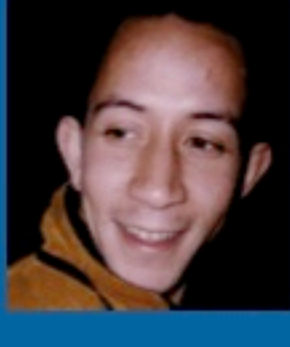


**The role of patients acting on the  
social determinants of health,  
promoting patient rights and  
improving patient experience.**

**Simon Collins  
i-Base.info**

The role of patients acting on the social determinants of health, promoting patient rights and improving patient experience.

*People* taking an active role in their health in the NHS.



Andrew, Andy B, Andy C, Chris M, Chris P, Richard, Chris W, Space, Nick, Dolly, Wesley, Colvin, Jimi, Kevin, Mike, Paul, Mark, Steve.

# Outline

- **HIV in the UK: 2014**
- **Patient/doctor collaboration**
- **Personal history**
- **UK advocacy – HIV i-Base**
- **Global access:**
  - **Treatment Action Group (New York)**
  - **Treatment Action Campaign (South Africa)**
- **Question session**

# HIV in the UK: 2014

- Public Health England
- 6250 diagnosis in 2013
- 3250 in MSM
- ~3000 heterosexual
- 16% MSM younger than 24 yo
- 10% MSM older than 50 yo



Public Health England:

<https://www.gov.uk/government/statistics/hiv-in-the-united-kingdom>

# World AIDS Day 2014

- Hunter Charlton
- Diagnosed in 2012
- age 20
- Gap year in Australia
- One exposure



The Independent (1 December 2014)

<http://www.independent.co.uk/life-style/health-and-families/features/world-aids-day-2014-this-is-what-hiv-looks-like-9894256.html>



# Young people and HIV

- “I mean I just always use a condom really... but of course you’ve been in a situation where you haven’t, I mean, everyone has.”



56 Dean Street Clinic

“Young people’s attitudes towards sex & HIV” (12 mins video)

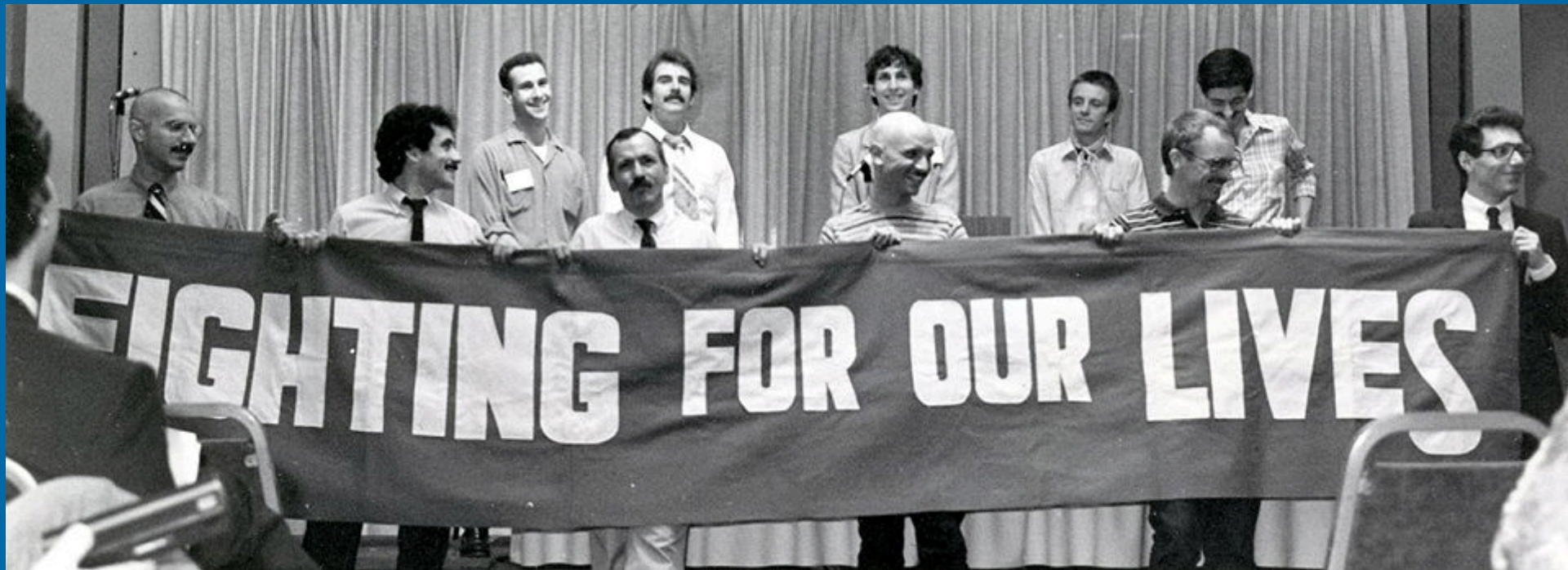
[https://www.youtube.com/watch?v=ThCO\\_8CcHmU](https://www.youtube.com/watch?v=ThCO_8CcHmU)

# Collaboration

- **Collaborative approach is essential.**
- **Reduce gap between clinical expertise and individual use.**
- **People should be able to receive care as partners in our own health.**
- **We (think as a patient) are likely to have the strongest interest in staying alive.**



# Denver principles, 1983



<http://www.actupny.org/documents/Denver.html>

# Denver principles, 1983

- We condemn attempts to label us as "victims".
- Be involved at every level of decision-making.
- Be included in all AIDS forums with equal credibility.
- Ethics: to inform and protect others
- Right to full explanations of all medical procedures and risks.
- To die--and to LIVE--in dignity.

<http://www.actupny.org/documents/Denver.html>

# Wide interest in care



**Limited:**  
**Doctor to**  
**decide**

**Active:**  
**Every**  
**decision**

**This can change over time as knowledge  
and information changes**

# patient:doctor dynamic

- **Strange situation**
- **Reliance on doctor as gatekeeper to care (treatment, health and life).**
- **Often specialised language – and potential cultural and class differences.**
- **All at a time of personal stress.**

# Why take an active role?

- **Better care: from appointments to treatment**
- **Interactions with health workers**
- **Access to treatment (choice and new medicines).**
- **Information and understanding.**
- **Shared decision making helps if future outcomes are worse.**

# Disadvantages

- **People are not always aware of these options.**
- **Many do not chose an active role.**
- **May be wrong in hindsight.**
- **Often needs confidence and persistence and to overcome fear of being a “difficult patient”**



# Personal history.1

- Likely HIV+ 1988/9.
- 1994: CD4 60 cells/mm<sup>3</sup>
- 1996: CD4 = 2.
- (range 400-1600 c/mm<sup>3</sup>)
- Cachexia, weight loss 45 kg
- Crypto/microspodia (MST 90 mg/d)
- Multiple OI's: CMV in both eyes
- ARVs: d4T/3TC/indinavir – expect no response.



# Personal history.2

- **Weight increased >1kg / week**
- **Energy returned**
- **Yr 1: CD4 = 100: stop CMV treatment**
- **Yr 2: CD4 = 200.**
- **Switch for side effects (kidney stones, lipoatrophy, toenails) and better formulations (TID> BD> QD)**

# AIDS Treatment Project (ATP)

- **1996: ~40 HIV+ people**
- **Volunteer phonenumber: “does treatment really work?”**
- **“every person is able to make their own treatment decisions”**
- **Dr Fax, conferences, internet – to reduce medical timeline**

# Early examples 1997/8

- **3 vs 2 drugs (including research)**
- **indivavir vs saquinavir: 63 vs 43%**
- **Viral suppression > drug resistance.**
- **Use of viral load and resistance tests**
- **Long-term vs short term benefit**
- **HAART for PMTCT,**
- **d4T and lipoatrophy**

# i-Base (April 2000)

- Medical meetings
- HIV Treatment Bulletin (HTB)
- HTB editions in S. Africa, Turkey, Balkans
- Treatment guides (>35 languages)
- Phonenumber and online Q&A
- UK-CAB



**VIH/SIDA**  
**Introdução à terapê**  
**de combinação**  
 Setembro de 2011

© I-Base agradece a revisão científica de Maria José Cardoso, Luis Mendonça e Ricardo Fernandes. Agradecemos a revisão de Ana Paiva, Gabriela Cohen, Rosa Freitas, Tradução: Mariana Romagosa

primeiras perguntas a pessoas seropositivas recentemente e advice received do tratamento

www.i-base.info  
 www.gapcrugal.org

**Rastreo da infeção pelo VIH e riscos de transmissão sexual**  
 outubro de 2013

Revisão Científica: Maria José Cardoso  
 Coordenação: Rosa Freitas  
 Tradução: Mariana Romagosa e Ricardo Fernandes  
 Projecto: Escola Europeia de Formação  
 Coordenação gráfica: Diogo Lourenço

www.i-base.info  
 www.gapcrugal.org

**Guide to HIV, pregnancy & women's health**  
 September 2011

**i-base**  
 0800 000 0015

HIV i-Base  
 0509 1415-9140  
 www.i-base.info  
 Watch for out-of-date information

Diagnosed with HIV in pregnancy  
 How HIV is transmitted to a baby  
 Mother's health  
 Having an HIV negative baby

**GUÍA PARA ENTENDER LAS PRUEBAS DE DETECCIÓN Y EL RIESGO EN LAS PRÁCTICAS SEXUALES**  
**TRANSMISIÓN SEXUAL DEL VIH**

www.i-base.info

**hiv tedavi bülteni**  
 türkiye Ağustos 2011 sayı:2

**EDİTÖRDEN** 03

**KONFERANS RAPORLARI** 04

04. **Webinarlar ve Fikirler** **Enfeksiyon Hastalıkları Kongresi - CROD**  
 27 Ocak - 2 Mart 2011, Boston, ABD

- HIV/AIDS tedavisinde ilaçların kullanımına ilişkin ilk bulgular
- Tibet'teki bir köydeki HIV hastalarında ART kullanımı üzerine CROD'den yapılan bulgular
- Antiretroviral ilaçların kullanımına ilişkin ilk bulgular
- Yeni doğan ve erken perinatal enfeksiyon bulguları ve tedavi
- Korunmasız cinsel ilişki: gebelik hastalıkları üzerine yapılan ilk bulgular, jinekolojik enfeksiyon bulguları
- PHSA çalışmalarının etkileriyle ilgili bulgular

**KONFERANS RAPORLARI** 15

15. **HIV Tedavisinde Klinik Farmakokinetiklerin Rolü** **Uluslararası Çalışma**  
 29-31 Nisan 2011, Miami, ABD

- Oral ve intravenöz ilaçların etkileri üzerine yapılan ilk bulgular
- Leptin/HIV ilişkisi üzerine yapılan ilk bulgular

**KONFERANS RAPORLARI** 27

27. **İngiliz HIV Tedavisinde Yeni Çalışmalar**  
 4-8 Nisan 2011, Birmingham, İngiltere

- Oral ve intravenöz ilaçların etkileri üzerine yapılan bulgular
- HIV/AIDS tedavisinde kullanılan ilaçların etkileri üzerine yapılan ilk bulgular
- Perinatal enfeksiyonla ilgili HIV enfeksiyonu

**PATOJENEZ** 20

- Tüberküloz enfeksiyonunun HIV enfeksiyonuna etkileri üzerine yapılan ilk bulgular
- HIV enfeksiyonuna ilişkin ilk bulgular
- HIV enfeksiyonuna ilişkin ilk bulgular

**TEDAVİ** 22

- HIV enfeksiyonunun tedavisi üzerine yapılan ilk bulgular
- Klinik ve laboratuvar bulgularına ilişkin ilk bulgular

**PROFLAKSİ** 23

- Oral ve intravenöz ilaçların etkileri üzerine yapılan ilk bulgular
- HIV enfeksiyonuna ilişkin ilk bulgular

**ÇOCUK SAĞLIĞI** 24

- Oral ve intravenöz ilaçların etkileri üzerine yapılan ilk bulgular
- HIV enfeksiyonuna ilişkin ilk bulgular

**TÜRKİYE'DEN SAYFALAR** 25

- HIV enfeksiyonunun tedavisi üzerine yapılan ilk bulgular
- HIV enfeksiyonuna ilişkin ilk bulgular

**I-BASE YAYINLARI** 25

**HALIM**  
 www.i-base.info

**i-Base.info**





i-Base.info

# UK-CAB (2002)



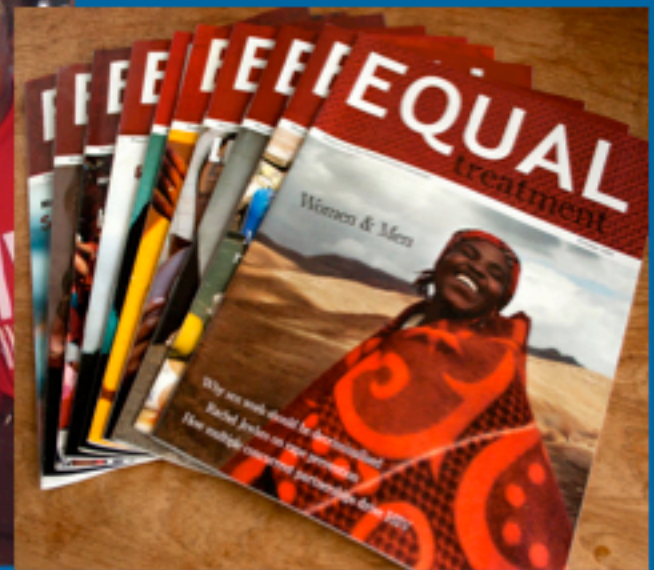
- Network of UK activists.
- Community Advisory Board ~ 600 members/120 organisations
- BHIVA guidelines and conferences
- Four meetings/year + online forum
- Language: HIV positive (not infected)
- [www.ukcab.net](http://www.ukcab.net)

# Global health and access

- “none of these drugs are for Africa”  
meetings with pharma co’s 1996-2000
- 2014: >12 million people on ART
- Generics and patents (Yusef Hamied,  
Cipla: \$10K/year to < \$1 a day
- Second-line drugs, new drugs, etc.
- d4T (neuropathy, lipoatrophy)

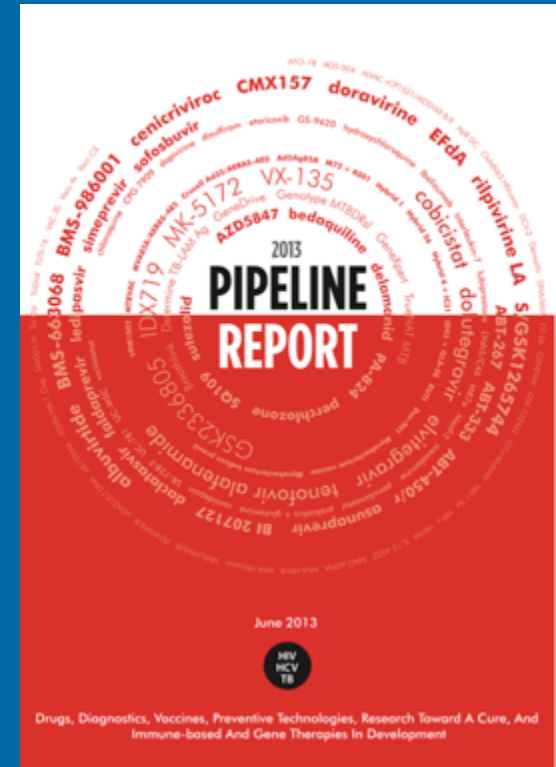


# Treatment Action Campaign



# TAG/i-Base pipeline reports

- Better drugs: more effective, easier to tolerate, less resistance
- Cost & access, paediatrics
- HCV and TB coinfections
- Cure research
- **PipelineReport.org**



# Current issues

- **Cure research**
- **Generics in the UK**
- **When to start treatment**
- **TasP: Treatment as Prevention**
- **PrEP: Pre-exposure prophylaxis**



Martin Delaney

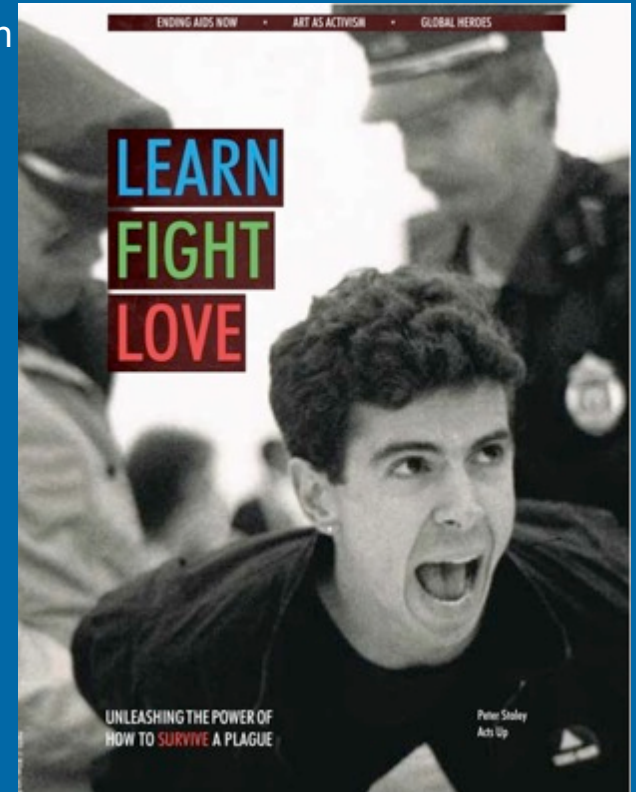


# Conclusion and summary

- **Powerful examples of where medical advances change peoples lives**
- **Powerful examples of where activism (community, health workers, politicians) show that change is possible.**

# Further watching

- **And the Band Played On** (also Jaffe talk with clips: <http://www.hivdrugtherapy.org>)
- **Angels in America**
- **Blue** (Derek Jarman)
- **Fire in the Blood** (Global access)
- **How to survive a plague (ACT-UP/TAG)**
- **Philadelphia**
- **Precious**
- **United in Anger (ACT-UP)**



# Thank you

## Time for questions

Thanks to Polly Clayden, Memory Sachikonye  
and Marc Ennals at i-Base.