### 40 Years: An HIV positive perspective





Simon Collins, HIV i-Base www.i-Base.info





The Worshipful Society of Apothecaries

### **Disclosure**

#### No personal financial conflict of interest



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

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# Background

- Nothing about HIV was expected.
- The 80s were a lively time.
- Dynamic political and social times.
- No-one expected
- to become a patient:

Expert or not.



# **Overview: positive history**

- Expert patients and peer support...
- Denver principles community engagement
- HIV+ representation: trials, guidelines and services.
- Treatment information for different people

## **Becoming active**

- HIV+ people we had the most to gain and most to lose from our treatment.
- Actively engaging, sharing 'patient-led' decisions.
- CD4 count, acronyms (CMV, KS, MAC, PCP, PML), then viral load and drug resistance and adherence. Always a choice.

## 'Active' rather than 'expert'

I made bad and good decisions:

- 3TC monotherapy on EAP just wrong.
- Stopping nuke monotherapy just luck.
- First person to stop CMV meds at CD4 100 (skill of Dr Suzanne Mitchell).

Being active means accepting responsibility for decisions for being right at the time.

## Denver principles (1983)

• Document that put HIV+ at the centre of care - and responsibility.



# • Supported by gay activists (Dr Joe Sonnabend and Dr Marcus Conant).

https://i-base.info/qa/factsheets/the-denver-principles-1983

# Denver principles (1983)

- Self empowerment, rights, dignity, respect.
- Involvement in all decisions about care, including treatment (or not).
- Language: "People living with HIV/AIDS".
- Also responsibilities.

https://i-base.info/qa/factsheets/the-denver-principles-1983

#### **Peer-led community organisations**



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### **Community resources**



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Editor - Paul Blanchard Medical Consultant - Dr Graeme Mayle, Chesses & Westminuter Hospita

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AIDS Treatment Project, 280 Kennington Lane, London, SE11 SRD 0171 793 7444 Fax: 9171 793 5300 Email: atp@dircon.co.uk



Body Positive, Positive Times, DrFax, ATU, Positive Nation.

## Peer support

- Early info about ART does it work?
  Are there side effects?
- Phone calls changed when HIV status became clear.



AIDS Treatment Project

- Benefits from working outside NHS.
- Early side effects (body changes), choice of PIs, d4T, New-Fill.

#### ATP and DrFax

AIDS Treatment Project (ATP) 1996-2000.

Led by people with experience of ART.

DrFax, edited by Paul Blanchard – faxed critical research news to doctors every two weeks.

Most other HIV organisations in the UK were atbest cautious and at worst were actively hostile to new drugs.





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Editor - Paul Blanchard Medical Consultant - Dr Graeme Moyle, Chelsea & Westminster Hospital

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This newsletter is provided to you free of charge courtexy of ATP, our donors, volunteers and sponsors.

We ask that you circulate it among your colleagues who might be interested.

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### **Community representation**

**BHIVA guidelines** - Community now included at all levels of BHIVA and on all guidelines.

- **MRC and other research** first plans, on all committees, including DSMBs.
- **Commissioning services.**
- Meaningful involvement (MIPA)

UK-CAB ukcab.net

Now >700 advocates. 70% HIV+ Founded in 2002. Focus treatment issues. Four training meetings a year (now over 70 are online).



# **Community goals**

- Focus on better treatment.
- Early access (EAP). Including price and choice.
- Five years wait after AZT for a second drug.
- 1997 20+ pills a day
  2007 Atripla 3-in-1 (note: Cipla 2003)
  2021 10 x single pill combinations

# 10 x single pill combinations



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# **Early ART issues**

- Triple > dual > monotherapy.
- Triple ART during pregnancy to reduce transmission.
- Goal of undetectable viral load to avoid resistance.
- Increased doses for children.
- Use more effective meds first.



## **Other timeline examples**

- 1981 1995+ viral load shows continuous viral replication - rather than 10 year period of latency.
- 1995 PrEP with TDF pre/post infection protected macaques from HIV PrEP approved 2012.
- 1998 US DHHS guidelines include early ART to reduce HIV transmission. 2008 Swiss Statement.
   PARTNER 2014. U=U 2016/7.
- 2000 "ART is not for Africa" Cipla generics, 3x5 to 24 million...

#### Treatment guides from 2000 - 2020



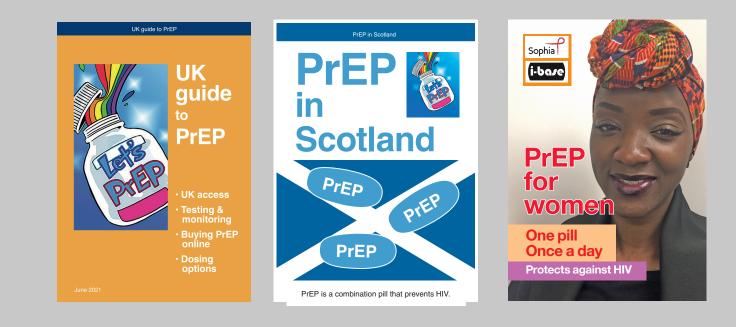
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#### Translations...



www.i-base.info

Recent resources on PreP



Posters individualised for different clinics

#### UNDETECTABLE viral load means HIV IS **UNTRANSMITTABLE** www.i-Base.info/u-equals-u **Rich Walkins** Bloomsbury Patient Rep & HT Health Promotion Office A person with su od cannot transmit HIV to their sexual partners.



#### Laura Waters, Consultant in HIV Mortimer Market Centre, British HIV Association (BHIVA)

\* Undetectable = Untransmittable Poster produced by HIV I-Base for Mortimer Market@CNWL (Feb 2019)

#### UNDETECTABLE viral load means HIV IS UNTRANSMITTABLE www.i-Base.info/u-equals-u



"A person with sustained undetectable levels of HIV in their blood cannot transmit HIV to their sexual partners."



Angelina Namit



Chloe Orkin, Chair, British HIV Association (BHIVA)

#### \* Undetectable = Untransmittable Poster produced by HIV - Base for Kobler@CWH (July 2018)

London Fast Track Cities: 40 years on - June 2021

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# Looking forward to zero

- Fast Track Cities in the UK works closely with many different HIV communities.
- They are optimistic targets and times.
- London at 95%, 98% and 97% was unthinkable a few years ago.
- The FTC campaign keeps HIV awareness.
  *For 2030, watch new PrEP for zero transmissions.* Zero preventable deaths and stigma are more difficult.

#### Thank you

#### **Questions?**

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## **Summary and thanks**

- Different 40-year histories will come from every country and groups of people affected by HIV.
- All community strength has been with dynamic support from nurses, doctors and researchers who were happy to teach us.
- Many medical professionals doctors, researcher, chemists, drug companies - are all driven by similar activist goals to overcome HIV.

#### Back-up slides

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## **Evidence 2015**

- START Study: benefits of ART at any CD4 count.
- Generated date for universal global access to treatment

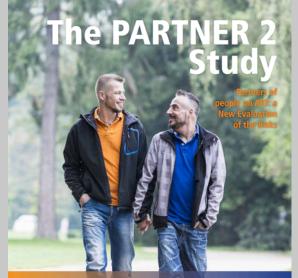
# Evidence 2014, 2016, 2018

http://i-base.info/htb/32308

PARTNER 1<sup>[6]</sup> & PARTNER 2<sup>[7]</sup>

ZERO after 53,000 times – gay and straight - no condoms

ZERO after 77,000 times - gay men only – no condoms [undetectable below 200 c/mL]



#### HIV positive with a negative partner? HIV negative with a positive partner?

ent has on reducing the risk of to know these risks, there are hardly any accurate studies

PARTNER

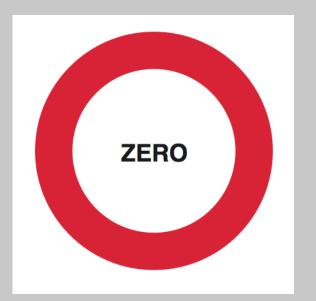
study is looking at the impact HIV The PARTNER study is looking for couples where positive and on treatment. The study will also look at erent patterns of condom use. All information m the study will be anonymised and will be in

www.chip.dk/partner

6. Rodgers A et al. CROI 2014 and JAMA 2016; 7. Rodgers A et al, IAS 2018 and

www.i-base.info

## **PARTNER studies**



PARTNER 1: zero transmissions after gay and straight couples had sex more than 56,000 times <sup>[1]</sup>

PARTNER 2: zero transmissions after gay couples had sex more than 77,000 times <sup>[2]</sup>

1. Rodgers A et al. CROI 2014 and JAMA 2016; 2. Rodgers A et al, IAS 2018 and The Lancet, 2019.

## **Adapting resources**

- Other histories from every country and groups of people affected by HIV.
- All community strength has been with dynamic support from doctors and researchers who were happy to teach us.
- Many medical professionals doctors, researcher, chemists, drug companies - are all driven by similar activist goals to overcome HIV.



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ase.i

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#### **U=U** Undetectable = Untransmittable

Did you know that having an undetectable viral load on HIV treatment (ART) stops HIV transmission?

ART is not only good for your health – it also protects your partners if they are negative.

U=U means that you don't need to use condoms if you were only using them to stop HIV transmission.

Leading UK doctors and researchers strongly support the U=U statement.

"A person with sustained, undetectable levels of HIV in their blood

cannot transmit HIV to their sexual partners."

Professor Chloe Orkin, Chair, British HIV Association

UK guidelines state that HIV doctors should talk to all their patients about how ART stops transmission.

#### What is U=U?

U=U stands for:

Undetectable = Untransmittable It means that someone with an undetectable HIV viral load on ART cannot transmit HIV, even without using condoms or PrEP.

#### What does U=U involve?

The protection from ART depends on:

- Taking ART to get an undetectable viral load. In the UK this means less than 50 copies/mL.
- Continuing to take your meds to keep your viral load undetectable.

#### How can U=U not be a risk?

This is because when viral load is undetectable in blood there is too little HIV in sexual fluids for transmission to occur.

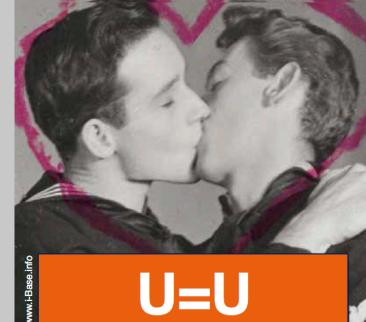
May 2019



\* Undetectable = Untransmittable

Free leaflets, postcards, to clinics and online:

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UEU undetectable viral load untransmittable

HIV

London Fast Track Cities: 40 years on - June 2021

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#### Tsai C-C et al, Science 1995

Daily weight-based daily PMPA (tenofovir) SC for one month in 35 macaques inoculated IV with SIV (10 x 50% infectious dose): 5 arms, follow up 40-56 weeks.

Dose	Day started	n	% infected
20mg/kg	48 hrs pre	n=5	0
30mg/kg	48 hrs pre	n=10	0
30mg/kg	4 hrs post	n=5	0
30mg/kg	24 hrs post	n=5	0
Control	48 hrs pre	n=10	100

1. Tsai C-C et al, Prevention of SIV Infection in Macaques by (R)-9-(2-Phosphonylmethoxypropyl)adenine. Science 1995. (NIH funded).