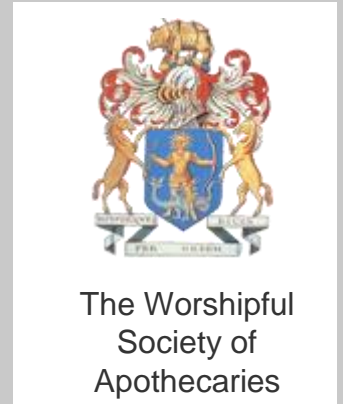


# 40 Years: An HIV positive perspective

23 June 2021



Simon Collins, HIV i-Base  
[www.i-Base.info](http://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.

# 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 activist doctors (Joe Sonnabend and Marcus Connant).

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

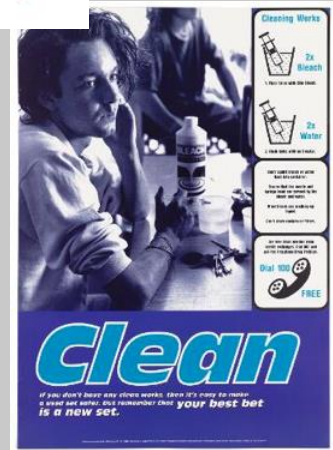
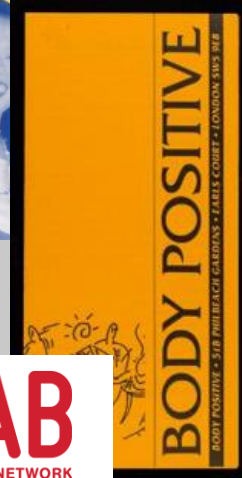
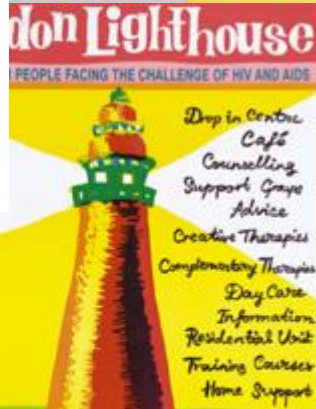


# Denver principles (1983)

- 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



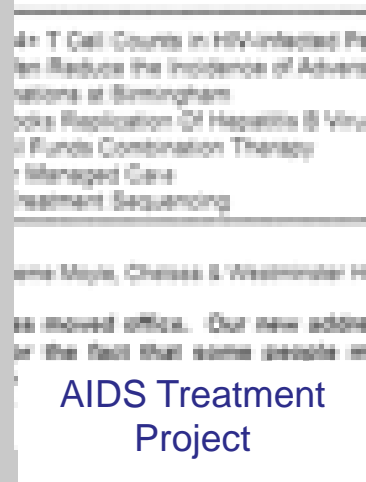
# Community resources



Body Positive, Positive Times, DrFax, ATP, Positive Nation.

# Peer support

- Early info about ART - does it work?  
Are there side effects?
- Phone calls changed when HIV status became clear.
- 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 at best cautious and at worst were actively hostile to new drugs.



**ISSUE 11 - Contents**  
22.11.96

---

IL-2 Therapy Doubles CD4+ T Cell Counts in HIV-Infected People  
Thalidomide and Ketoconazole Reduce the Incidence of Adverse Events of Interleukin-2  
Nevirapine Based Combinations at Birmingham  
Lamivudine Effectively Blocks Replication Of Hepatitis B Virus in HIV-Infected Men  
Better CD in Brazil? Brazil Funds Combination Therapy  
Survival Decreases Under Managed Care  
CURRENT OPINIONS - Treatment Sequencing

---

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

Please note that ATP has moved offices. Our new address is at the bottom of this page. We apologise for the fact that some people may not have received this newsletter during the process of moving, particularly if you had requested delivery via email. Please call or fax us if you missed any issues or pages.

The AIDS Treatment Project is a group of mostly HIV positive people who are working to improve access to and information about promising new treatments against HIV and AIDS. With this information people with HIV can decide for themselves if, how and when to use these treatments.

The AIDS Treatment Project does not advocate any particular treatment, or even treatment over no treatment against HIV and AIDS. It does advocate informed treatment choices. Its guiding principle is that all HIV positive people in the UK can understand enough about HIV itself and about HIV treatments to make their own treatment decisions.

AIDS Treatment Project is also involving HIV positive people in helping to shape the future of AIDS research. The Doctor Fax is an attempt to ensure that those involved in the treatment of people with HIV and AIDS have the opportunity to receive the most up-to-date information which we deem to be of importance to our care.

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

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

AIDS Treatment Project, 180 Kensington Lane, London, SE11 8RD 0171 793 7444  
Fax: 0171 793 8300 Email: atp@dircon.co.uk

# 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



Atripla,



Biktarvy,



Delstrigo,



Dovato,



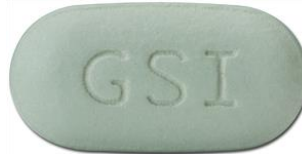
Eviplera,



Juluca,



Odefsey,



Stribild,



Symtuza,



Triumeq

# 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

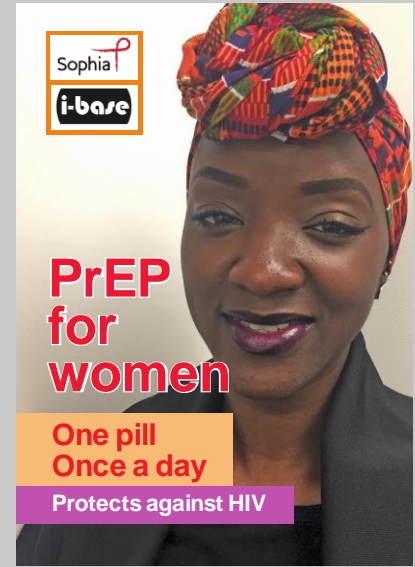
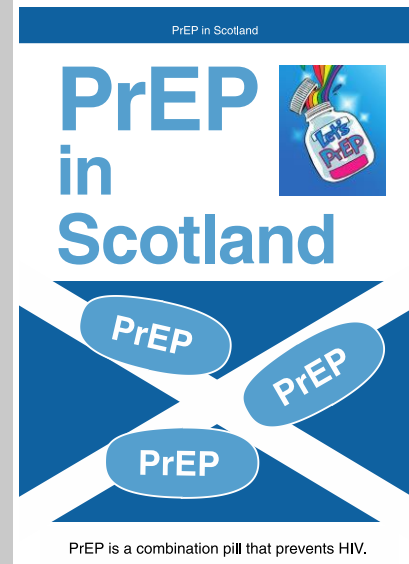
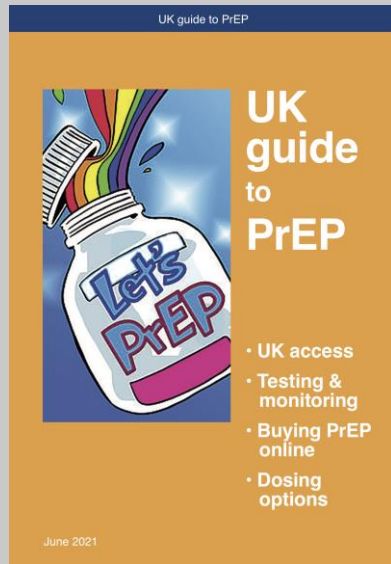
- 1981 - 1995+ viral load shows continuous viral replication - rather than 10 year period of latency.
- 1995 - PrEP with TDF pre/post infection protected macaques from HIV - PrEP approved 2012.
- 1998 - US DHHS guidelines include early ART to reduce HIV transmission. 2008 Swiss Statement. PARTNER 2014.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

# Treatment guides from 2000 - 2020





# Recent resources on PreP



Posters  
individualised  
for different  
clinics

**U=U\***  
**UNDETECTABLE**  
**viral load** means **HIV IS**  
**UNTRANSMITTABLE**  
[www.i-Base.info/u-equals-u](http://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.**

**Rich Watkins,**  
Bloomsbury Patient Rep &  
THT Health Promotion Officer

**Michelle Ross,**  
dmit

**Angeline Namiba,**  
Salamander Trust

**Ray Trevillion,**  
HIV i-Base

**Lizara Walters,**  
Consultant to HIV  
Mortimer Market Centre,  
British HIV Association  
(BHVA)

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

**U=U\***  
**UNDETECTABLE**  
**viral load** means **HIV IS**  
**UNTRANSMITTABLE**  
[www.i-Base.info/u-equals-u](http://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."**

**Michelle Ross,**  
dmit

**Angeline Namiba,**  
Salamander Trust

**Simon Collins,**  
HIV i-Base

**Clare Orkin,**  
Chair, British HIV Association  
(BHVA)

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

# 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?

[www.i-Base.info](http://www.i-Base.info)



**i-base**  
HIV treatment  
information  
service

Calls are free from  
land lines and most  
mobile networks.  
All calls are  
confidential.

**ASK A QUESTION**  
by phone, email or online

**0808 800 6013**  
[questions@i-base.org.uk](mailto:questions@i-base.org.uk)  
[www.i-base.info](http://www.i-base.info)

Information to be used in discussion with your doctor. Registered charity no: 1081905.

The poster features a large white and orange pill graphic in the center. The background is light blue with several small, colorful circles (yellow, green, pink, blue) scattered around the pill. The text is in white and orange, matching the pill's colors.

# 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

# 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 [6] & PARTNER 2 [7]

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]*

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



**The PARTNER 2 Study**

Partners of people on ART: a New Evaluation of the Risks

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

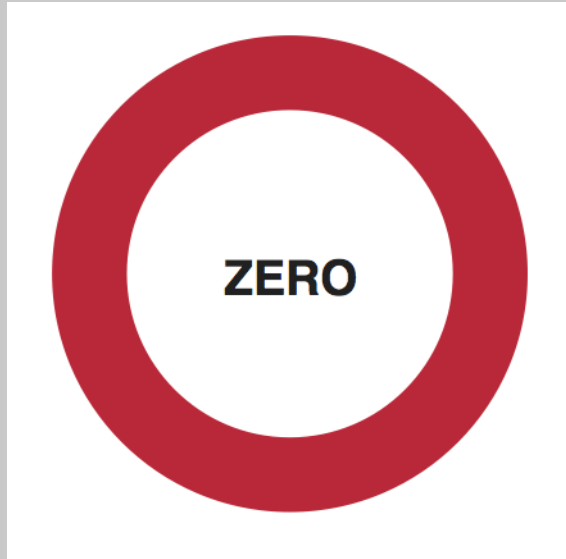
A study is looking at the impact HIV treatment has on reducing the risk of HIV transmission. While everyone wants to know these risks, there are hardly any accurate studies.

The PARTNER study is looking for couples where one partner is HIV negative and the other is HIV positive and on treatment. The study will also look at the different patterns of condom use. All information from the study will be anonymised and will be in confidence.

 PARTNER

[www.chip.dk/partner](http://www.chip.dk/partner)

# 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.

## 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

www.i-Base.info/u-equals-u

## U=U \*

**UNDETECTABLE  
viral load means HIV IS  
UNTRANSMITTABLE**

\* Undetectable = Untransmittable

Free leaflets,  
postcards, to  
clinics and  
online:  
**i-Base.info**



www.i-Base.info

**U=U**  
undetectable  
viral load  
**=**  
untransmittable  
**HIV**



# 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).