Early community involvement 1981-1998

Simon Collins www.i-Base.info

BHIVA conference 22 – 24 November 2020

S Collins: www.i-base.info

UK-CAB: January 2020

Disclosure

No personal financial conflicts of interest.

Some projects at i-Base are supported by research-based companies including Gilead, Janssen, Merck and ViiV.

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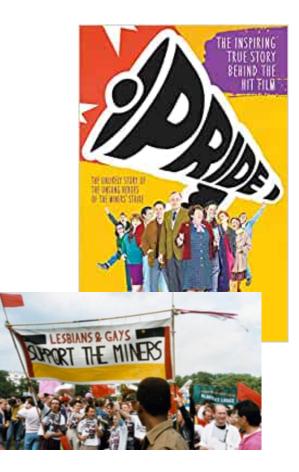
Background

Apologies: Subjective, London-based, white, gay, male perspective...

1980s were divisive. Privatisation of coal, steel, gas, water, electricity, BA, airports, rail etc. (Funded tax cuts for business and the wealthy, who donated to one political party). Four million unemployed. Social policy on "family values".

NHS, Royal Mail and air were narrowly saved.

Community: anti-racism, anti-apartheid and the miners strike. Some local Labour councils challenged central government and supported lesbian and gay rights.



Mainstream Media: sexist, racist homophobic - fuelled fear & discrimination

Slide: Jo Manchester and Jane Shepherd

sample of the deadly virus and was sente



Timeline 1 - First responses

Unless you were directly affect by HIV, the UK was behind the US by several years.

There was sex before HIV – and low awareness meant this that continued to the mid 80s.

July 1982: Terry Higgins died Nov 1982: First article in Capital Gay 1983: early Terry Higgins Trust meeting in Conway Hall that included Jonathan Grimshaw and Dr Ian Weller.

1983: AIDS Action Group

Dec 1984 – THT safer sex leaflet included not having sex with Americans or people who were ill.



Nov 1982

But from 1983/4 first reports in Capital Gay were in single and then double figures (compared to many thousands in the US).

> Fifteen hundred in White House vigil

President the widespread concern over the illness, and to press for greater federal funding and research. AIDS sufferers at the head of the march were the first to light their candles. Half a dozen of them addressed a rally in front of the Capitol at the end of the procession. Similar vigils took place in cities across the United States on the day of the Washington event. · In Scotland too there was a small

gathering of Scottish Homosexua Rights Group members timed to coincide with the American vigils. About 20 people met on Edinburgh' Mound on a damp and windy Saturday evening. They were groened with a mixture of cheers, derision and car horns from people alerted to the event by the local press. SHRG members stood in silence holding candles as a mark of respect for the victims of AIDS



Dec 1984



HIV Provention England Enhrupey 2020

Political AIDS group being started

A group is being launched in London to provide a political response to the disease AIDS (Acquired Immuno-deficiency Syndrome).

Jeff Vernon, one of the people behind the new group, which is appealing for members, tells us: "The Terrence Higgins Trust was set up to support victims of AIDS and their friends. Other work of a campaigning nature remains to be done;namely collecting facts about AIDS, monitoring media coverage and responding misinformation, educating the public, and encouraging medical research into AIDS."

Anyone interested can write to: Medical Group, c/o CHE, 274 Upper Street, London N1 2UA.

Timeline 2: Community

Fundraising – peer support

- 1984 THT becomes a charity, first helpline.
- 1985 Body Positive later expanded to many local and regional groups - first HIV test, first candlelit vigil.
- 1986 AVERT education in schools £237 for TH
- 1986 CRUSAID (Kobler Centre and Walk for Life marches)

Bolts raises E237 for the Terry Higgins Trust which is tackling problems caused by the disease AIDS. The benefit on Thursday included a show with The Harlequeens, Sandy Rogers, Rebel Rebel, Sheena Sean and compere Martin Russell. It was the last time Lazers will be called Bolts on a Thursday. From last night (Thursday) it is the home of the Stepping Back Club. Bolts continues on

Fridays and Saturdays

Rockshots raises £1,000 for THT

ROCKSHOTS club in Newcastle raised £1,000 at a benefit on Monday night to help the Terry Higgins Trust.

Biggest-ever cheque for AIDS Trust

> Portland Arms raises £505 for Higgins Trust

> > day after David Date t. He was due to have

Pickle come

d finished his act, He was due to have peared as 'High Society' with dirella, but Addrella was prevented in appearing by a heavy cold. corepting the donation on behalf of 'Trust was Trust member Tons interead who congranulared David d his friends on their efforts

Early reports: prevention and treatment

Reports analysing prevention and treated included articles by Julian Meldrum and Tony Whitehead.

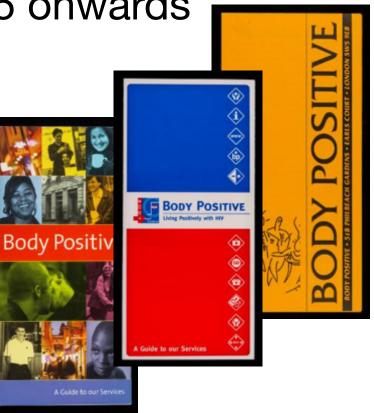


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Body Positive – 1985 onwards

Self-help, peer support, phoneline, small grants Youth group Women's group Drop In Centre Lunch meals

Newsletter – no. 240 (nov 1999) Many local organisations in the UK: Lincs, Dorset, Blackpool (94), Birmingham (89), Wear, Cheshire & N Wales, Somerset, Derbyshire, Brighton, Hertfordshire, Cardiff, Bedfordshire, Shropshire, Kent, Thames Valley, Devon, Mid Sussex, BP North East, BP North West.



London Lighthouse – 1986

Pioneering centre for respite and palliative care - when people with HIV were being turned away from existing hospice services. (Model for Bethany Trust, Sussex Beacon etc)





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Timeline.3 Late 80s: Key projects for diversity

- 1986 Birchgrove Group
- 1987 National AIDS Trust.
- 1987 National AIDS Manual.
- 1987 Positively Women, Mark Ashton Trust.
- 1988 London Lighthouse.
- 1988 Kobler Clinic
- 1988 Blackliners
- 1988 Food Chain
- 1989 Mainliners
- 1989 Frontliners



Birchgrove Group – 1986

- Sept 1983 first haemophilia cases in UK. 1985-91 – Legal action (MacFarlane Trust)
- 1986 Mary Dykes supports Birchgrove meetings in Cardiff – different to Haemophilia Society.
- 1988 provides peer support services and fundraising for residential support
- and relaxation weekends.
- 1990 expands to Manchester and London.
- 1993 First conference.
- 1996 First trees bought.
- 2004 Woodland opens

https://www.birchgrovegroup.org



Slide: Robert James

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Positively Women – 1987

By and for HIV positive women

1987 – Spare Rib interview

1991 – leaflet for women's drop-in support service



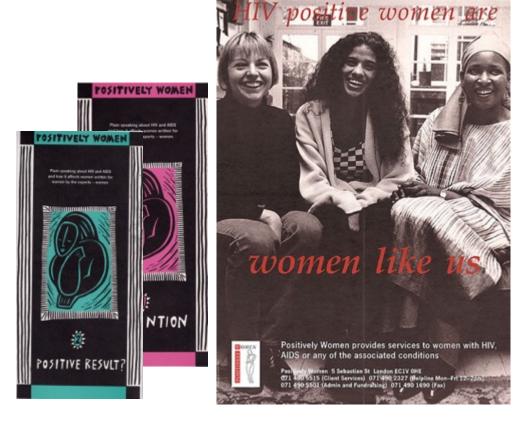


Slide: Jo Manchester and Jane Shepherd

By and for HIV positive women 2:

Resources produced by and for women living with HIV, London 1990 and 1992

Produced by Positively Women.



Slide: Jo Manchester and Jane Shepherd

By and for HIV positive women 3:

Awareness booklet for young women, Cardiff, UK, 1990. Cardiff AIDS Helpline.

A Positive Woman's Survival Kit, London, UK, 1999 ICW



A Positive Woman's Survival Kit

This Kit is dedicated to all HIV positive women in the world. Each of us is a special human being. Each of us deserves to be treated with respect and dignity.



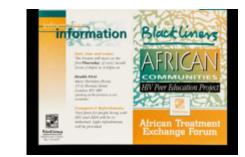
Slide: Jo Manchester and Jane Shepherd

BCAT 1986, Blackliners – 1988

HIV prevention and support for African, Caribbean and Asian communities.

Developed from the Black Communities AIDS Team (BCAT, 1986): mixed group mainly for black and Asian gay/bi men.





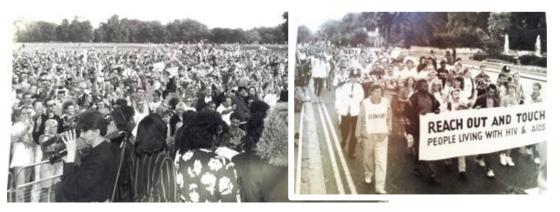


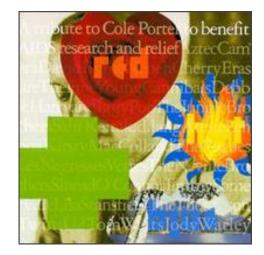
Red, Hot and Blue (1990)

Tribute fundraiser, Simon Watney.

Reach Out and Touch (1991)

Community concert – ft Whitney Houston Largest HIV march and vigil, Vernal Scott.





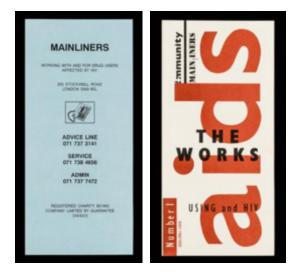


Photographs: Vernal Scott

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Mainliners - 1989

Specialist support for people who inject drugs





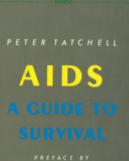


S Collins: www.i-base.info

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1987: 32 UK AIDS helplines

AIDS: A guide to survival, Peter Tatchell, 1987



DR CHARLES FARTHING

> UPDATED NEW EDITION

AIDS Helplines

ABERDEEN - see 'GRAMPIAN'

BELFAST 'AIDS Belfast' c/o Cara friend, PO Box 44, Belfast, BTI 1SH (0232) 226117, Friday, 7.30-10.30pm

BIRMINGHAM 'AIDS Line West Midlands' Hazeleigh, 79 Stanmore Road, Edgbaston, B16 9SU (021) 622 1511, Tuesday/ Thursday 7.30 – 10pm

BOURNEMOUTH 'AIDS Help Line' PO Box 263, Bournemouth BH8 8DY (0202) 424442, weekdays, 8– 10pm

BRADFORD 'West Yorkshire AIDS Information Exchange' (0274) 732939, Wednesday/ Friday, 7.30-9.30pm

BRIGHTON 'Sussex AIDS Helpline' PO Box 17, Brighton BN2 SNQ (0273) 734316, weekdays, 8– 10pm

BRISTOL 'Aled Richards Trust' 1 Mark Lane, Bristol BS1 4XR (0272) 273436, Thursday, 7– 9pm

CAMBRIDGE 'AIDS Helpline' PO Box 257, Cambridge CB2 1XQ (0223) 69765, Tuesday/ Wednesday, 7.30–10.30pm

CARDIFF - 'AIDS Helpline' (0222) 223443, weekdays, 7-10pm

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CHICHESTER 'CALM' PO Box 11, Bognor Regis, West Sussex, PO21 1AH (0243) 776998, Monday/ Wednesday/Friday, 7.30-10pm

COVENTRY 'AIDS Helpline' (0203) 714144, Monday, 7– 10pm

CUMBRIA 'Cumbria & the Borders Gay Community' (059) 681 244, weekdays, 7– 8pm

DUNDEE 'AIDS Helpline' (0343) 25083, weekdays, 9am-5pm

EDINBURGH & GLASGOW 'Scottish AIDS Monitoe' PO Box 160, Edinburgh EH1 3UU Edinburgh (031) 558 1167, Monday/Tuesday/Thursday/ Friday, 7.30-10pm

Glasgow (041) 221 7467, Tuesday, 7–10pm GRAMPIAN 'AIDS Line'

PO Box 250, Aberdeen (0224) 574000, Tuesday/ Friday, 7-10pm

GUILDFORD 'AIDS Line' (0483) 300150, Tuesday-Friday 8-10pm, Sunday 3-5pm

GWENT 'AIDS Helplines' Caerleon (0633) 422 532, Tuesday, 2–8pm Newport (0633) 841 901, weekdays excluding Thursdays, 8.30am-4.30pm HARROGATE 'AIDS Concern North Yorkshire' A.C.N.Y., PO Box 117, Harrogate, HG2 0TA (0423) 505222, Monday/ Thursday, 7–9pm

HILLINGDON 'AIDS Helpline' (0895) 74606, weekdays, 4– 6pm

LEEDS 'AIDS Helpline' c/o 'Rockshots 2', 64–68 Call Lane, Leeds 2 (0532) 441661, Tuesday, 7– 9pm

LEEDS 'AIDS Advice' PO Box HP7, Leeds LS6 1PD (0532) 444209, Monday/ Thursday, 7-9pm

LEICESTER 'AIDS Inquiries' via Gay Switchboard (0533) 550667, weekdays, 7.30-10.30pm

LIVERPOOL 'Merseyside AIDS Support Group' 63 Sharmock Road, Birkenhead, L41 0EG (051) 708 0234, Wednesday, 7–10pen (051) 246 8089 – recorded message with details of STD clinics and AIDS support groups. LONDON 'Terrence Higgins Trust' BM AIDS, London WC1N 3XX (01) 242 1010, every day, 3–

10pm MANCHESTER 'AIDS Line' PO Box 201, Manchester M60 1PU

(061) 228 1617, weekdays, 7– 10pm MILTON KEYNES 'AIDS Help Line' PO Box 153, Wolverton, Milton Keynes (0908) 312196, Monday, 7– 9pm

NEWCASTLE 'AIDS North' Box NE99 1BD, Newcastle (091)232 2855, Wednesday/ Friday, 7–10pm

NEWPORT 'AIDS Line' (0633) 841 901, weekdays, 8.30am-4.30pm

NORWICH 'AIDS Helpline' (0603) 615816, Thursday, 8– 10pm

NOTTINGHAM 'AIDS Information Project' c/o CNS, 33 Mansfield Road, Nottingham NG1 3SS (0602) 585526, Monday/ Tuesday, 7–10pm

OXFORD 'OXAIDS' FreePost, Nether Westcote, OX7 6BR (0865) 246036, weekdays, 10-12 noom/1-5pm Harrison Dept., Ra3cliffe Infirmary, Woodstock Road, Wednesdays 6-8pm

PLYMOUTH 'AIDS Helpline' (0752) 663609, weekdays, 10am-6.30pm

READING 'AIDS Line' PO Box 75, Reading, Berks (0734) 503377, Thursday, 8– 10pm

SOUTHAMPTON 'AIDS Line'

c/o Solent Gay Switchboard, PO Box 139, Southampton SO9 7JE (0703) 37363, Tuesday/ Thursday/Saturday, 7.30– 10pm

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Timeline.4 1990s

- 1990 Black HIV/AIDS Forum (Manchester)
- 1991 LEAN (London East AIDS Network) – now Positive East.
- 1992 Naz foundation & NAM updates
- 1993 UK Coalition of People Living with HIV
- (Published Positive Nation and Back to Work project)
- 1994 Scottish Voluntary HIV and AIDS Forum (HIV Scotland)
- 1996 AIDS Treatment Project (ATP) Treatment activist organisation peer led.
- 1996 Body & soul.
- *Plus numerous African support groups (see next slide).* 1997 – First BHIVA guidelines.



African support groups

Many African support groups included

- Africa Advocacy Foundation
- African Community Involvement Association (ACIA)
- African HIV Policy Network (AHPN)
- BHAF (Black HIV/AIDS Forum)
- Black Health Agency
- HIV/AIDS Association of Zambia
- Ugandan AIDS Advocacy Foundation
- Uganda Community Relief Association
- Vanguard





Naz – 1992

Support group and services for HIV positive people from BAME communities.



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Publications 1996 -



International 🖒



ATP DrFax #11 – (Nov 1996) Body Positive #226 (Sep 1998) Positive Nation #40 (March 1999) Positive Times #39 (July 1998)



ISSUE 11 - Contents

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Editor - Paul Banchard Medical Consultant - Dr Graeme Move, Charasa & Westminuter Housita

Please note that ATP has moved offics. Our new address is at the bottom of this plage. We applogues for the fact that some people may not have nearied the during the process of moving, particularly if you had requested delivery

via email. Please cell or fax us if you missed any insure or pepes. The ADS Treatment Propel is a group of monthy HV positive people sho an extrag to improve access to and internation adult promong new treatments quantit HV and IXDE. With the internation people with HV are proved for thermologing in the set of the memory.

The AIDS Treatment Project does not advocate any particular treatment, or even treatment over no treatment against HVI and AIDS. It does advocate informed treatment charace. To particle principle as their all HVI positive people. In the UK can understand enough allocd HVI feel and allocat HVI treatments to make their own handment decisions.

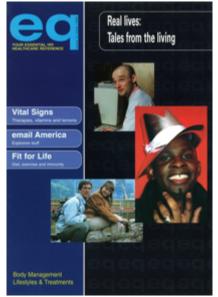
AD5 Transmer Project is also involving WV prelifive people in folging to shape the future of AD5 measure. The Dollar Pas is an interval to ensure that those involved in the treatment of people with RV and AD5 face the opportunity to resolve the most up-to-date information which we deem to be of importance to our sam.

This neededan's provided to provide or charge contemp of ATP, our storers, volutions and approach. We ask that you constrain a storers your colosponer who might be impresent.

AIDS Treatment Project, 280 Kennington Lane, London. SE11 SRD: 0171 763 7444 Fax: 0171 783 8300 Email: stp@dircon.co.uk



Publications





EQ#11 (John Stevens) 1999, ATU from 1992, Continuum (Denialist) 1996

S Collins: www.i-base.info

HIV Prevention England – February 2020

BHIVA Conference November 2020

ratory illness

MINUM

ATP 1996

AIDS Treatment Project (ATP)

Peer organisation of people who personally benefited form combination therapy.

DrFax –compilation of latest treatment news faxed to doctors every two weeks.

Volunteer-based treatment information phoneline. Could say treatment worked – at a time when many other HIV organisation were at-best cautious of treatment and at worst were actively hostile.



Summary 1998

By 1998 – when HAART was widely available, hundreds of community organisations had been set up across the UK. Apologies to the many who I have not been able to include.

More than 50 African support groups in London.

More than 30 branches of Body Positive across the UK.

National publications: Positive Nation, Dr Fax, NAM, Body Positive, Positive Treatment News, Positive Times, Equilibrium, Continuum (denialist) many organisation newsletters.

Many of these have no internet history (please keep your archives).

In Memory





Simon Mwendapole, Uganda AIDS Action Foundation (UAAF)

and

Paul Blanchard, Founded the Chapman Clinic. First editor of ATP's Dr Fax and i-Base's HIV Treatment Bulletin (HTB)

HIV Prevention England – February 2021

Thanks

Robert James, Hope Mhereza, Badru Male, Graham McKerrow, Simon Watney, Ash Kotak, Vernal Scott, Kate Thompson, Jo Manchester and Jane Shepherd, Polly Clayden, UK CAB. Wellcome Trust (for some images).

Questions...



Flyposting 1987, S Collins

UK-CAB: January 2020

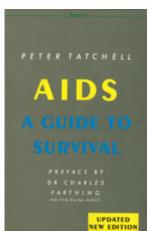
Back-up slides

S Collins: www.i-base.info

UK-CAB: January 2020

AIDS: A guide to survival, Peter Tatchell, 1987

Mental imagery: Imagining sharks chasing infections.



ince to be int and full of chergy.

- 6) Now visualise your body fighting back against AIDS in symbolic fantasy form:
 - * You could, for example, picture the AIDS viruses/opportunistic infections/cancers as a small group of languid squids and your defender cells as a huge shoal of sharks. Imagine the sharks ferociously devouring *all* the squids and not letting a single one escape. Then picture the sharks swimming away and the sea becoming totally tranquil and crystal clear to reveal an exotic wonderland of filagree corals and tiny multicoloured fish shimmering in the warm aquamarine waters.



 * An alternative symbolism could be based on warfare - 'AIDS Wars' - in which the defender cells are represented by buge

Early events

Community activism included getting information from the US (3 years ahead), prevention work in different communities (safer sex) and fundraising events.

- 1981 first cases reported in the US and the UK.
- 1982 Terry Higgins died in July.
- 1983 AIDS Action Group.
- 1983 First THT meeting at Conway Hall,
- 1983 Panorama and Horizon "Killer in the village".



Horizon 1983: Bobbi Campbell, HIV positive nurse, coauthor of Denver Principles

Early safer sex: THT 1984

1. Have sex with fewer men.

2. Avoid anal sex, except possibly with your regular partner.

3. Have sex only with men whom you know to be in good health and who have had few other sexual partners. 4: Avoid sex with men who have been sexually active in North America in the last three years. 5. Since the virus has been found even in saliva, perhaps the only safe sex is mutual masturbation. body rubbing and dry kissing.