

'No Decision
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Making a difference in HIV
POSITIVELY
UK

HIV Networks

There are a number of HIV networks established to promote the sharing of information, and support people with their and well-being, and engagement in activism. This paper provides an overview of these networks. It is not intended as a definitive guide, but an introduction to what is available:

CHIVA

The Children's HIV Association was funded by Elton John AIDS Foundation to develop its website to act as an umbrella for information relating to children, families and HIV. The project will finish in March 2012, but the site now has a number of newly developed areas including an area for parent's which explores issues parent's told us through consultation (disclosure, schools, talking to your child); a secure website made for and by HIV positive young people; a resource library; medical guidelines and a networks area which sets out the family health services across the UK and Ireland.

Additionally to this, CHIVA have commissioned the build of an independent disclosure website specifically for parent's to use with their uninfected children. As this is still all in development, CHIVA welcome all comments and feedback.

www.chiva.org.uk.

Ffena

Ffena is a network of Africans in the UK living with and affected by HIV. The network enables African people living with HIV in the UK to share their experiences of living with the virus and make their voices heard. Ffena is a Luganda word meaning '[we] all together'. Ffena aims to enable African people living with and affected by HIV to participate meaningfully in AHPN activities and the wider policy society and make their voices heard. The Ffena network is the only national network of African people living with and affected by HIV. Ffena informs and invigorates the African Health Policy Network's work in policy, research and practice. By interacting with and learning from Africans in the UK living with and affected by HIV and sexual health conditions, AHPN gains greater understanding of the particular issues and concerns that affect them.

<http://www.ahpn.org/ffena>

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Forum Link

The Forum Link began in 2004 in response to the changing clinical and treatment environment of patients living with HIV, and the growing number of HIV patient groups, service user groups, and patient & public engagement sub groups (PPE) involved in developing services. While retaining a strong HIV positive person-centred ethos, services focus on strengthening HIV patient group representation in both service delivery and development locally, regionally and nationally in line with the UK government's Patient Public Involvement Strategy of 2010.

The Forum Link's mission is to provide a coordinated ***"voice for HIV patient groups across the UK"***, and beyond. Currently The Forum Link has grown to over a dozen individual clinical patient groups representing several thousands of patients accessing treatment centres across the country. Collectively, The Forum Link represents a substantial percentage of the UK's HIV positive community. This number will increase substantially in time and also expanding to include European groups who increasingly recruit Forum Link's expertise to replicate the model.

www.forum-link.org/

HIV Activists Network

The Network has been set up to give people living with HIV a greater voice on issues that matter to them. Some people shy away from the term 'activist', thinking they need to be loud, visible, and knowledgeable on complex subjects. With NAT's HIV Activists Network you don't need to be any of these. All you need to take part is a desire to bring about change. Taking part can involve anything from letter writing to face-to-face interactions, and NAT is here to guide you on how you can get active.

This is an opportunity for you to have your say on the matters you feel strongly about. NAT regularly identifies issues that people living with HIV have told us are important, and HIV activists can choose which one(s) they get involved with. Current topics include changes to HIV prescribing in London, benefit cuts and social care. It's very easy to take action - NAT will provide you with information on key issues, supporting materials and contact details.

Contact HIVactivist@nat.org.uk / 020 7814 6767

www.nat.org.uk

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myhiv

The myhiv website offers a range free online services, tools and community spaces tailored to your personal needs. The site offers information and support services from the Terrence Higgins Trust, personal experiences of living with HIV via videos, stories and diaries and the opportunity to link into national and local peer support via the Community Forums message boards. People living with HIV that register to the site can:

- Connect with others living with HIV and find relevant local services
- Take control of meds and appointments with text/email reminders
- Track & understand your CD4 and Viral Load with graphs
- Improve your knowledge of HIV
- Take part in consultations and campaigns relating to HIV
- Share your experiences and help others

www.myhiv.org.uk

PozFem-UK

PozFem-UK is a national network of women living with HIV who have a desire to be advocates for the rights of women living with HIV in the UK. The network is run by women with HIV for women with HIV. We aim to meet and train so that together we can develop the skills and the confidence to influence decisions that affect us. We are a very diverse group of women and we want to make sure that the complex needs, visions and realities that spring from our lives, through all the different stages, from adolescence, to motherhood and old age, are addressed in policy, in the media and in social and scientific research. At the moment we operate through a closed yahoo group. If you wish to join the list serve please contact Silvia Petretti on

spetretti@positivelyuk.org

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UK Community Advisory Board (UK-CAB)

UK-CAB is a network for community HIV treatment advocates across the UK that was set up in May 2002.

The 3 main aims of the UK-CAB are to:

- Develop and strengthen a network of treatment advocates
- Provide expert training on current treatment issues and opportunities to meet with doctors, researchers and pharmaceutical companies
- Develop community representation in clinical trials and setting the standard of care

UK-CAB connects over 440 members from over 120 organisations via a web-based message board and face-to-face meetings.

The message board enables members to contribute to clinical trials design, comment on treatment guidelines, communicate with other advocates and keep up to date with reports on the latest research.

Membership is free to join and open to HIV-positive people and community advocates. A valid email account is needed to take part. To join go to:

<http://www.ukcab.net/join/>