

Power to the Patients

The Patient can be as knowledgeable as the expert, but is uniquely placed to have a holistic view of their condition.

Annual report 1999 - 2000

Company information

Directors:

Colin Webb, Dr Ruth Webb

Company secretary:

Terry White

Accountants:

H. Brumger, Spreadsheet Solutions, 5 The Windings, Sanderstead, Surrey, CR02 0HW

Bankers:

National Westminster Bank, Paddington Branch, PO Box 2795, 26 Spring Street, London W2 1WE

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Company Registration number:

3850575

VAT Number:

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Staff

Valentina Grecchi

Volunteers

Clifton Hardy, September 1999 to February 2000

Georgia Greenaway, March 2000 to October 2000

Bona Lumbe, January 2001 (to date)

Positive Futures (6 month work placements)

John Hirrell, April 2000

Robin Joseph, June 2000 (ongoing)

Executive Summary

The European Coalition of Positive People (ECP) is a coalition of people living with HIV and Hepatitis infection in the European Union (EU). We are a Patient Group¹, and meet the European Union definitions of an NGO², representing people living with HIV in the EU. We have been deeply involved in issues such as Biotechnology, Standards of Care, Harmonisation of the Pharmaceutical Regulation between member states, Equity of Access in the EU, Rational Prescribing, Clinical Trials and Access to Medicines both in the EU, the Applicant States to the EU and the developing world.

Who we are

The ECP is a self-help organisation of, by and for people living with HIV and Hepatitis C. We are a London-based NGO. All our members are living with HIV1/HIV2/Hepatitis C.

Who we represent

We are a loosely associated organisation, with many crossover links with other agencies such as the European Public Health Forum, TB Network Association, International Patients Organisation, Central & East European Harm Reduction Network, European AIDS Treatment Group, the Global Network of Positive People and the International Community of Women. We seek to represent the interests of patients living with HIV and Hepatitis C on a range of issues including: - harmonisation of regulation and equitable access to medicinal products across all member states, clinical trials, standards of care and biotechnology.

Mission in Europe

We believe that people living with HIV and Hepatitis C should be central to the relevant debates about health and social policy. We are seeking to establish a democratic and accountable patient voice at a European level and promote patient involvement in the development of public policy and the planning, delivery and monitoring of services.

Values

1. Our ethos is one of self-help. We believe that people living with HIV and AIDS, Hepatitis C, etc, should be central to the relevant debates about health and social policy. **People who have the right information, backup and role models, can deal effectively with the world on their own or with each other's support.** The organisation must be run by, controlled by and represented by positive people.

¹ A Patient Group is defined as genuinely representing the needs of patients as consumers of health care. Patients Groups are run by patients, for patients and are represented by patients. (International Alliance Patients Organisations)

² Comprehensive Report, European Forum Social Policy 98, Brussels 24-26.6.98; European Commission;

Aims

1. To provide a means by which people living with HIV & AIDS, and Hepatitis C can be heard & represented.
2. To inform and educate those within the European Coalition and beyond by the dissemination of appropriate information.
3. To campaign and advocate for the interests of people living with HIV, Hepatitis C and Tuberculosis, challenging that which adversely affects their welfare.
4. To strengthen and further develop the Coalition to enable it to achieve its mission.

Objectives

1. To work with others to influence governmental policy in such areas as human, civil and disability rights, immigration & migration access to health care, treatments, standards of care, and social policy.
2. To promote user involvement in the development of public policy and the planning, delivery and monitoring of services.
3. To influence the regulatory authorities, the pharmaceutical industry and medical treatment system, on such issues, as biotechnology, drug trials, drug development, drugs access, pricing, etc.
4. To encourage and assist in the development of local & national groups of positive people.
5. To further establish and strengthen the European Coalition and secure its resource base.

Major issues of concern

- Research on and treatment for, Hepatitis C.
- Access to treatments:-

The European Union - The harmonisation of the pharmaceutical industry regulatory processes and the EMEA. So that treatments, once approved by the EMEA, should be available in all member states at the same time.

The Applicant States to the Union, that once approved all available Treatments are fully available.

In the developing world – see our separate position paper.

- Clinical Trials.
- Support for Vaccine development.
- The enlarged EU and public health issues.
- Biotechnology, Bioethics and genetic engineering. In 2001, Stem Cell Research.
- End of life issues.
- Pharmaceutical drug pricing, differential pricing, parallel trading & patent protection.

- Standards of care and in hospital treatment across Europe.

Activities in the last 3 years

- We currently hold a joint contract with the EU (funding for 2000/2001) in Association with AIDES Federation Nationale, France, on a project entitled “European Back to Work Project, Raising Standards at Work for People Living with HIV and AIDS”.
- We are part of the European Federation of Pharmaceutical Industries Associations, “The Patient/Industry Think Tank”. As part of this body we are;
 - Chair of the subcommittee of “Access to Medicine in the Developing World”.
 - Members of the subcommittee on “Sources of Patient Information in the EU”.
- We are involved in the Access to Medicines debate. We are working in three main areas: the Member states (on regulatory systems), Applicant States to the EU, and Central and Southern Africa. Some key activities have included;
 1. Negotiating with the Treatment Activists in South Africa, Ministry of Health & Pharma on access to anti-retrovirals for HIV treatments, and Fluconazole.
 2. Funding the Co-ordinator of Treatment Action Campaign of South Africa.
 3. Advised the British Cabinet Office – “Performance and Innovation Unit” on their preparation for the G8 meeting at Genoa, July 2001.
 4. Networking and visiting ACT-UP Chapters in Washington DC, New York, Philadelphia, and San Francisco.
- A policy seminar in Prague from 3-4 November was held addressing the issues of communicable diseases for the Applicant States of the European Union. It held as its main theme the involvement and development of civil society (community based, and patient led organisations) in the development of policy and planning and delivery of services. The Chair was John Bowis MEP, of the EU Parliamentary Committee on the Environment, Public Health and Consumer Policy.
- We held a joint conference with EFPIA³ and 4 other patient groups⁴ on “Getting Better, Developing mechanisms to ensure the best benefit for patients from medical progress” held in Brussels, November 24, 1999. Mr B Hansen, Mr Gouvrais and Dr F Lutz of the Commission and Mr Heppel, Chair of the EMEA participated.
- We worked with various other patient groups and lobbied the European Parliament to pass the “Directive for the Legal Protection of Biotechnological Inventions” – Directive 98/44/EC.
- Member of the European Parliament Biotechnology Working Group.
- We actively participate in various conferences and Round tables, pertaining to our core interest. These included:-

³ European Federation of Pharmaceutical Industries Associations.

⁴ European Alliance for Genetic Services, European patients Voice, European Organisation for Rare Disorders and the Global Alliance of Mental Illness Advocacy Networks,

The Bangerman Round Table, Paris, 1998;

Medicinal Products & Public Health Conference, organised by the Portuguese Presidency 1999, Lisbon.

High Level Round Table on Communicable Diseases 28 Sept 2000, organised by the WHO, UNAIDS and the EU Commission in Brussels.

ACP-European Union Joint Parliamentary Assembly 12 October 2000

The XIII World AIDS Conference in Durban 2000.

- Advise on security arraignments at XIII World AIDS Conference, Durban July 2000.
- Position papers on “Access to Medicines” and “Enlargement and HIV”, the EU Public Health Forum.
- Working with the All Party Parliamentary Group on AIDS, (British Parliament, cross party working group).
- Members of the European Public Health Alliance.

Selection of Conferences & Meetings attended

- International Hepatitis C Conference, London, November 1999
- Increasing Access to Essential Drugs in a Globalised Economy, Amsterdam , November 1999
- Medicinal Products and Public Health, The Amsterdam Treaty and the Future of the European System of Evaluation and Supervision of Medicinal Products, Lisbon, April 2000
- The WTO and Implications of the EU’s Global Trade Policy on Health, Brussels, April 2000
- HIV/AIDS and Social and Economic Development, International Development Committee, House of Commons, London, April 2000
- European AIDS Treatment Group, General Assembly, May 2000
- European Parliament, Committee on the Environment, Public Health and Consumer Policy, Public Hearing on Public Health and Consumer Policy, Aspects of Enlargement, Brussels, July 2000
- XIII World AIDS Conference in Durban, July 2000
- EU, WHO & UNAIDS High Level Round Table, on “Accelerated Action Targeted at Major Communicable Diseases within the Context of Poverty Reduction: HIV/AIDS, Malaria and Tuberculosis, Brussels, September 2000
- Fifth International Congress on HIV, Glasgow, December 2000.

Plans for 2001

In the United Kingdom

We will continue our working with the All Party Parliamentary Group.

We will continue our work with the British Governments (Cabinet Office) "Performance and Innovation Unit" on their preparation for the G8 meeting at Genoa, July 2001, and their subsequent work.

In the European Union

Overall, we will pursue our activities in the EU, in all aspects of patient rights and health care, principally in the area of access to medicines and public health, where the EU does have competency.

- Harmonisation of the regulatory processes is a core element of the access to medicines debate. The "Central Registration Process", by the European Medicines Evaluation Agency and the Mutual Recognition" Procedure are not as effective as they could be in enabling rapid access to new medicinal products as they could be.
- Delays of up to five years can occur in medicinal product availability between the various Member States. This unequal access is against the existing Treaty Obligations. It is also palpably unacceptable that patients can access medicines unequally in the different states, this is obvious to internal migrants and holidaymakers.
- We will continue our work on the Clinical Trials directive implementation within national legislation.
- We will continue our work on Biotechnology, monitoring the implementation of the Directive in all member states.
- We will actively follow and influence the formation of the Public Health Forum of the EU Commission.
- We will work with the EU Temporary Parliamentary Committee on Human Genetics and new Technologies in Modern Medicine, 30 Jan 2001 to 12 November 2001.

In the Applicant states to the European Union

The Applicant States are the "poor relatives" of the soon to be enlarged EU. Health care spending is on average 4% of GDP while within the EU it is 8% of GDP. We are concerned, as the epidemic rises that these countries will no longer be able to fund unlimited, full, HAART⁵.

Our broader concerns about equity and the recognition procedures within the EU are also relevant within the enlarged EU.

We are concerned about the Public health impact on the EU of enlargement. Poland, Hungary, Slovakia, and Romania all have co-terminus borders with the Ukraine. The Ukraine, has a near a pandemic with 1.63% of active young males infected with HIV, poses risks to the applicant states and therefore there is the risk to the EU as a whole. One barrier to the spread of HIV by immigrant populations has been regarded as "assimilation" issues, such as language, culture, colour, etc. But within the applicant states there are between 380,000 and 700,000 Ukrainians already resident. This will facilitate Ukrainian immigration (legal and

⁵ Highly Advanced Antiretroviral Therapy, usually three anti-HIV drugs simultaneously. This can be 5 drugs or more.

illegal) entry into the EU and its applicant states, as resident Ukrainian populations will potentially enable easier assimilation from a “pandemic” country, allowing “bridging transmission” of HIV.

In Africa

We anticipate continue funding Treatment Action Campaign.

We anticipate concluding our negotiations to hold a meeting between Treatment Activists, Pharma and the South African Ministry of Health.

We will maintain our watching brief on the issues of access to medicines in sub Saharan Africa. We are consulting with relevant and interested parties on the issue.

Follow on from Prague 2000

We propose to establish a set of relationships with various NGO’s within the applicant states.

We propose to hold a joint conference in 2001 on the Public Health and Enlargement issues.

Colin Webb BSc (Hons)

A 58 year old totally committed European. Diagnosed 1993 with both HIV1 and HIV2. British Army, enlisted 1960, commissioned Parachute Regiment 1963, Military Cross 1964, Military Advisor Commonwealth of Nations 1979-1989, retired as Colonel 1989. Co-founder of HINTS, Director UK Coalition of People Living with HIV and AIDS. He is the Executive Director of the European Coalition of Positive People. Director Empower Publishing. He has extensive lobbying experience of the European Parliament and the European Commission.

Dr Ruth Webb

A qualified veterinary surgeon, she has practised both in UK and in Africa. Diagnosed with HIV in March 1993, she has two children, Sarah born February 1998 and Anna born May 2000. Currently she is Chairman of the UK Coalition of People Living with HIV & AIDS, and of the European Coalition of Positive People. Member of various organisations including the Board member of Positive Nation, International Community of Women, the British HIV and AIDS (BHIVA) Executive Committee, and the Royal College of General Practitioners Working Party on HIV.

Terry White, MSc, MRI

Currently Director Business Affairs for the European Coalition of Positive People. Prior to entering the HIV sector in 1990, a successful manager in the commercial leisure industry in the USA for 8 years. 1990-1994 Business Affairs manager for the London Borough of Brent's HIV and Physical Disability Unit. 1993 Founder and co-founder of the UK Coalition of People Living with HIV and AIDS, the UK's leading patient led, policy and lobbying agency. 1995 Co-founder of Empower Publishing, which produces the UK's top HIV magazine, Positive Nation. 1994 Co-founder and Trustee of the Denholm Elliott Project, a registered Charity in the UK and a Fundacion in Spain. It offers care on the Island of Ibiza.

Valentina Grecchi

Born in Frankfurt/Main. Completed BA (Hons) in Business Studies at University of Westminster. Worked as administrator and marketing manager in the commercial sector till 1995/6. Since then has worked as administrator and PA for the AIDS Treatment Project and the UK Coalition of People Living with HIV and AIDS. Has joined the team at the European Coalition of Positive People in January 2000.