

## From the Chairman

The Year 2001 was a year of preparation in many ways for the Coalition.

We continued to be heavily involved in various relevant issues in the EU parliament, including Biotechnology, Stem Cell Research, Medicines for Children, Orphan Drugs and Information to Patients. The last mentioned exploded on to the agenda towards the end of the year and promises to be an ongoing topic for some time to come!

We continue to be actively involved in the Access to Medicines Debate – both within the EU and on a wider international level with regards to the Third World. There continues to be inequity of access to new medicines even within the EU, and the pricing issues are not resolved. Meanwhile, the problems in the Third World are regularly on the agenda.

In June 2001 we had representation at the UNGASS on AIDS, and the end result of that Special Session was the setting up of the Global Fund to tackle problems of HIV, TB and Malaria world-wide, but especially in the Third World. We continue to take part in the debates, which inform the management of the Global Fund, and press for more NEW funds to be allocated by the wealthier nations including those in the EU.

This year saw the completion of our funding for the South African organisation TAC, and the start of our preparations for projects in the Ukraine and Russia. This included visits to both countries.

Our concern about Public Health continues to be a major part of our work and we have been actively involved with EPHA all year. There is a growing awareness of the meaning of “patient representation” largely as a result of our presence at various fora. This is leading to an increase in the number of requests we get for participation in meetings related to Public Health and patient representation.

In all, the year 2001 stands out as a year of consolidation, preparation and participation for ECPP.

Dr Ruth Webb, BVetMed, MRCVS  
Chairman

## Executive Director's Report

The Year 2001 was one of increased activity both in EU and beyond.

The preparation for our Ukraine project was demanding, with several visits to Kiev. Eastern Europe is becoming a future area of operation. We also continue to be involved in the setting up of projects in Sub-Saharan Africa, with an emphasis on Malawi. Our lobbying continued on relevant issues in the EU parliament, including Biotechnology, Stem Cell Research, Medicines for Children, Orphan Drugs; and the Information to Patients debate began to heat up at the end of the year. Our stand on this issue is that it is a basic human right for patients to receive accurate, up to date information on Treatment options.

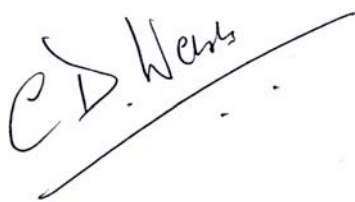
The Access to Medicines Debate – both within the EU and on a wider international level with regards to the Third World still rages on, there continues to be inequity of access to new medicines even within the borders of the EU, pricing issues are still to be resolved. Meanwhile, the access problems in the Developing World are regularly on the agenda.

In June 2001 we sent a delegation to UNGASS on AIDS in New York, and the end result of that Special Session was the setting up of the Global Fund to tackle problems of HIV, TB and Malaria in the Developing World. We continue to press for a considerable increase in the money to be allocated by the wealthier nations including those in the EU.

The arena of Public Health continues to be a crucial part of our activity. There is a wide debate on who should represent the interest of patients to the European Commission, largely as a result of pressure from ourselves, and other similar organisations. We strongly feel that this should be from the patients through their own organisations, and not from other self appointed bodies.

ECPP continues to be involved in dialogue with all parties regarding the enlargement of the European Union, and the possible effects of public health issues.

2001 has been an interesting and busy year for ECPP.

A handwritten signature in black ink, appearing to read 'C. Webb', with a long horizontal line extending to the right from the end of the signature.

Colin Webb BSc (Hons)

Executive Director

## Company information

**Directors:**

Colin Webb, Dr Ruth Webb

**Company secretary:**

Terry White

**Accountants:**

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**Bankers:**

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**Company Registration number:**

3850575

**VAT Number:**

BG 749 1042 35

**Charity registration no:**

1090117

**Staff**

Valentina Grecchi

**Volunteers**

John Campbell May 2001 (to date)

Bona Lumbe, January 2001 (to date)

Damallie Lwanga September 2001 (to date)

## 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 Group<sup>1</sup>, and meet the European Union definitions of an NGO<sup>2</sup>, 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 represent

We are a loosely associated organisation, with many crossover links with other agencies such as the European Public Health Forum, the European Federation of Neurological Associations, 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, All-Ukraine Network of People Living with HIV and AIDS, GAMIAN, Multiple Sclerosis Europe, Euro-Ataxia, etc. We seek to represent the interests of patients 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.

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## Mission in Europe

We believe that patients 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

Our ethos is one of self-help. We believe that patients should be central to the relevant debates about health and social policy. **Patients who have the right information, backup and role models, can deal effectively with the world on their own or with each other's support.**

### 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 patients. To further establish and strengthen the European Coalition and secure its resource base.

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<sup>1</sup> 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)

<sup>2</sup> Comprehensive Report, European Forum Social Policy 98, Brussels 24-26.6.98; European Commission

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# Activities 2002

## In the European Union

### Back to work

We currently hold a joint contract with the EU (funding for 2000/2002) 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". The project proceeded according to plan with activities involving the UK Coalition, THT-Lighthouse, The Globe Centre, and Positive Women. A national conference, to be held in London, is planned for February 2002, and a pan European Conference, to be held in Milan, is being planned for June 2002. The final report on the project findings is due in October 2002.

### Patient Pharmaceutical Industry Think Tank

We are part of the European Federation of Pharmaceutical Industries Associations, "The Patient/Industry Think Tank". As part of this body we are;

Co-Chair of the subcommittee of "Access to Medicine in the Developing World".

Members of the subcommittee on "Sources of Patient Information in the EU".

Member of the European Parliament Biotechnology Working Group.

### European Public Health Forum

On 16 May 2000, the European Commission adopted a Communication on "the health strategy for the European Union" and a proposal for an EU action program in the field of public health<sup>3</sup>.

This health strategy, and the public health action programme as its core instrument, will bring about a substantial reform of European health policy. Not only does the action programme provide for a more horizontal approach to improving the health of EU citizens, but it also, for the first time, explicitly commits to consultation with a wide range of stakeholders in the health community. We produced our own position paper on the subject and submitted it to the Commission<sup>4</sup>.

### Stem Cell Research

As patients, we believe that this research should take place using the best possible cells with the highest possible level of stability and safety: human embryonic stem cells.

We submitted to the Commission our own position paper on the issue, recommending the extensive expert work of the British House of Lords, and their report. A copy is on our web site.

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<sup>3</sup> Commission paper (COM 2000/285)

<sup>4</sup> Copy of the paper is available on our web site

## Information to Patients

We believe that ALL patients, no matter their condition, background or nationality, have a fundamental and legitimate human right of access to all kinds of information about their health, medical conditions and the availability of treatments including knowledge of the best available management for their disease. It is a question of solidarity, equity and patients' rights.

From our perspective EU patients/citizens need factually accurate, reliable, easily understandable information to be able to make informed decisions. They need to understand their condition and do want to receive information on treatments available. A copy of our position paper is available on our web site.

## International

### Access to medicines

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;

- Negotiating with the Treatment Activists in South Africa, Ministry of Health & Pharma on access to anti-retrovirals for HIV treatments, and Fluconazole.
- We part funded the Co-ordinator of Treatment Action Campaign of South Africa.
- Advised the British Cabinet Office – “Performance and Innovation Unit” on their preparation for the G8 meeting at Genoa, July 2001.
- We attended various fora including the TRIPS Council in Geneva, and gave a patients perspective on the WTO, TRIPS and the DOHAR round of negotiations.

### UNGASS

We attended UNGASS and participated in the various activities and made our contributions.



Spirit of Ukraine, Independence Square, Kyiv

## Ukraine

After contacts made at our 2000 Prague Conference<sup>5</sup> two visits were made to Ukraine by a team. Meetings and negotiations were held with the All-Ukraine Network of People Living with HIV and AIDS. From these meetings a two-year capacity development programme was devised. This includes elements of training (7 weeks for 20 people), mentoring, and core funding of a central office in Kyiv with 5 staff. There will also be a pan Ukraine PWA conference in Crimea, September 2003.

The project is due to start in March 2002.



Sergey Fedorov (Odessa), Vladimir Zhovtyak (Poltava), Olena Panfilova (Kyiv) and Artur Ovsepyan (Odessa) Members of the All-Ukraine Network's Co-ordination Council

We would like to acknowledge the support of the British Council and the EU delegation in making our visits useful and fruitful and to CAP for providing the translator.

## Russia

In association with the Elton John AIDS Foundation, the ECPP made two visits to Russia to assess the needs, capacity and viability of the nascent Network of People

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<sup>5</sup> Copy of conference report available on request

Living with HIV and AIDS. To ascertain, if, with the right support, could mobilise to become effective advocates for positive change in the life of PWA's within Russia.

A capacity development programme was formulated. We expect to start on this project in late 2002.



Left to right: Terry White, Roman Dudnik, Artur Ovsepyan, Iulia Zhovtyak Stephen Bitti, Vladimir Zhovtyak (Ukraine Network), John Campbell<sup>6</sup>.

Malawi

Two exploratory visits were made to Malawi, to ascertain the possibility of a project.

## Other activities

We launched our **web site** in August, which includes all our position papers, reports and links. <http://www.ecpp.co.uk>

We became a **registered charity** under UK charitable law.

We gave our comments on "Communication on the proposed, Programme of Community Action in the field of public health 2001-2006" to Rapporteur Trakatellis.

We worked with the All Party Parliamentary Group on AIDS, (British Parliament, cross party working group).

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<sup>6</sup> Members of the 4 networks (ECP, All Ukraine Network, Russian Network and UK Coalition), meeting at the Second Annual Conference: "Seizing Our Window of Opportunity in the Fight against HIV/AIDS" Hosted by: AIDS Infoshare, UNICEF and the Ministry of Health of the Russian Federation.