

# EUROPEAN COALITION OF POSITIVE PEOPLE

## annual report 2006



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## WE WOULD LIKE TO ACKNOWLEDGE OUR SUPPORTERS:

Abbott Laboratories	Pfizer Foundation
Bristol-Myers Squibb (BMS)	World Health Organisation (WHO)
Comic Relief	Nyewood Infant School, Bognor Regis
EFPIA	Cheselbourne First School, Dorset
Elton John AIDS Foundation	Pagham Church Ladies Club
European Parliament	St Thomas A Becket Church, Bognor Regis
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GlaxoSmithKline (GSK)	
Merck Sharp & Dohme (MSD)	
Pfizer	

Hello and welcome to my contribution to this year's Annual Report. It has been a hectic year for all of us at ECPP.

In Europe we continued to attend Think Tank meetings in Brussels. The debate about the use of primates in medical research seems to be raising its head again. In addition, the provision of information to patients continues to be an issue for all Europe.

There was continued activity in Russia, with another visit by myself to participate in a series of "Café Scientifique" seminars. This time I visited other parts of Russia rather than just Moscow.

This year saw the end of our involvement in Ukraine and we wish the Ukrainian Network all the best in its continuing activities.

Our work in Malawi continued apace, and there were a number of visits by various members of ECPP throughout the year. There was another visit by a number of Roche employees in June, which went very well. I was delighted to be able to visit the projects there in October.

There were further visits to Uganda but little progress has been made and we may decide to scale down our activities until things are more settled politically. Our project manager remains in Uganda monitoring things there.

There have been no staff changes at the London office this year, but we have increased staff in Malawi, as we have completed a further centre ( Tipewe ) and we are gaining two more members to the Board of Directors, which will be a welcome support.

Overall 2006 was a year of lively but steady progress.



Dr Ruth Webb,  
Chairman



*Ruth Webb  
Chairman*

**D**ear all,  
Here is the Executive Director's statement for 2006!

It was a very lively one on the Brussels front, with 'Information to Patients' taking up the lions share of the European activity. It now looks as if nothing really substantial will happen regarding this very emotive issue until 2009. I suspect this is because the European Commission is attempting to please all of the people all of the time, but is ending up pleasing hardly anybody, except the people who want no change at all, even though the European Commission has been charged with coming up with some changes by early 2007. We wish them luck in their endeavours!

We carried on in Russia, with two more visits from myself, and one from the chairman.

2006 saw the completion of our programme in Ukraine and we are proud to have contributed to the development of the Network.

Our work in Africa has been increased, with Malawi being the most active. We have opened one more orphan centre (Tipewe at Muliba Village) bringing the total so far to six, with one more to go. It really is a great pleasure working with the Malawian children, and it brings home to all of us at ECPP how much our work there is appreciated. Understanding the cultures and tradition has been one big challenge that makes our work even more interesting. HIV is still a taboo and trying to get the community to openly disclose their status is still a hurdle. Cultural practices such as Chinamwali seem to be upheld despite the complex spread of HIV that prevails. This practise encourages young girls as young as eight years to engage in sex in order to cleanse themselves of their young bodies, hence early marriages. This year we have encouraged more girls to stay on in school and are planning an educational programme.

Uganda is still motoring along, although at a somewhat slow rate, and it may be that we will scale back a little until the situation in the north of the country is more stable, although office facilities will be kept open until further notice.

In our London head office we are carrying our normal support role for our various projects.

We are looking forward to welcoming our new board members in the near future!

Although 2006 was a year of a lot of hard work, and with it some frustrations, it has turned out to be a year of gradual progression.



*Colin Webb*  
Executive Director

  
Colin Webb,  
Executive Director

### TRUSTEES

Dr Ruth Webb, Colin Webb

### ACCOUNTANTS/AUDITORS

Elan & Co, Chartered Certified Accountants  
Unit 3 Cedar Court, 1 Royal Oak Yard, London SE1 3GA

### BANKERS

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

### SOLICITORS

Dobsons Solicitors  
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### REGISTERED OFFICE

2 Whitehorse Mews  
37 Westminster Bridge Road  
London SE1 7QD

### CHARITY REGISTRATION NUMBER

1090117

### COMPANY REGISTRATION NUMBER

3850575 (a not for profit company)

### VAT NUMBER

GB 749 1042 35

### STAFF

Joan D'Souza, Director of Operations  
Valentina Grecchi, Web Developer & IT Manager  
Musharraf Khan, Bookkeeper  
Mayuri Naidu, Receptionist

The European Coalition of Positive People (ECPP) 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 greatly involved in issues such as Biotechnology, Standards of Care, HIV & Human Rights, 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, the Newly Independent States (NIS) and the developing world.

In 2006 we have continued to expand our networking capacity both within the European Union.

ECPP works in Europe, mainly promoting patient involvement in the development of public policy, delivery and monitoring of services. Where appropriate, building networks of People Living with HIV and AIDS.

In Europe we continue to actively participate in the Information To Patients debate.

This has enabled us to assess the different political legislative and regulatory frameworks in the different countries that impinge on patients both directly and indirectly.

In Malawi and Mozambique, ECPP promotes community participation in project development & implementation, supports orphan care projects within the home-based care programmes whilst maintaining co-operation with all key players in the fight against HIV/AIDS.

In Uganda we started up a treatment programme for people living with HIV as well as a youth programme involving skills training and empowerment.

<sup>1</sup> A Patient Group is defined as genuinely representing the needs of patients as consumers of healthcare. Patients Groups are run by patients, for patients and are represented by patients. (International Alliance of Patients' Organisations)

<sup>2</sup> Comprehensive Report, European Forum Social Policy 98, Brussels 24-26 June 1998; European Commission

## Network Partners

We have many crossover links with other organisations these include: European Public Health Alliance, European Patients' Forum, European Federation of Neurological Associations, TB Network Association, International Alliance of Patients' Organisation, European AIDS Treatment Group, All-Ukrainian Network of People Living with HIV and AIDS, GAMIAN, Multiple Sclerosis Europe, Euro-Ataxia, Community of People Living with HIV and AIDS Moscow, Association with AIDES Fédération Nationale France, ABRACO Portugal, UK Coalition, THT-Lighthouse UK, Lila Cadius Italy, Federation Estatal de Escuelas de Prevencion de Sida Spain, Centre for Inspirational Living Greece, HIV Vereniging Nederland, Project Hope, Imperial College, Royal Free Hospital, London School of Hygiene and Tropical Medicine, British Council (UK), the British Council (Ukraine), MANASO (Malawi), CONGOMA, MASAF (Malawi Social Fund), NUSAF (Northern Ugandan Social Action Fund) and the Ministry of Gender and Social Development in Uganda.

**W**e 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 national and international level, promoting patient involvement in the development of public policy and the planning, delivery and monitoring of services.

### VALUES

**O**ur 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.

### ORGANISATIONAL AIMS

**T**o establish such projects as may be deemed necessary to relieve the suffering of people living with HIV and AIDS.  
The protection and preservation of health.

### ORGANISATIONAL OBJECTIVES

**T**o work with other stakeholders to influence governmental policy in such areas as human, civil and disability rights, immigration and migration, access to health care and treatments, standards of care and social policy.

To influence the regulatory authorities, the pharmaceutical industry and the medical treatment system on such issues as biotechnology, drug trials, drug development, drugs access, pricing, animal testing etc.

To promote user involvement in the development of public policy and the planning, delivery and monitoring of services.

To encourage and assist in the development of local, national and international groups of patients.

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

## EUROPEAN UNION

In Europe our work has concentrated around the Access to Medicines, Animal Testing and Stem Cells & Biotechnology debates. We continue to work with the Patient Pharmaceutical Industry Think Tank, the European Patients' Forum (EPF), European Federation of Pharmaceutical Industries and Associations (EFPIA), European Public Health Alliance (EPHA) and the Association of the British Pharmaceutical Industry (ABPI). Additionally, we were involved in the drug resistance and salvage therapy campaign.

ECPP appointed the communications and marketing company, De Facto to write the organisation's position paper on the above areas.

### ACCESS TO MEDICINES

In the Access to Medicines debate we are continuing working in the following main areas: the EU member states (on regulatory systems), the Newly Independent States (NIS) and Sub-Saharan Africa.

In the EU member states, ECPP is involved in the salvage therapy campaign as recent studies show that prevalence of HIV infection is on the rise in Europe and increasingly individuals are infected with HIV drug resistant strains.

This is challenging the successful management of HIV infected patients. It decreases the effectiveness of treatment often leading to treatment failure. This is why we continue to need new drugs to fight HIV infection.

In Sub Saharan Africa, access to medicine is still a widespread problem, with governments unable to afford the cost of providing treatment especially to HIV positive people. We have worked with local clinics in providing anti retroviral treatment to the most remote areas in Northern Uganda in order to alleviate the burden on government.

The issue of safe medicines in Europe is high on the agenda. Most European patients take medicines believing that regardless of their efficacy, they are above all safe.

### INFORMATION TO PATIENTS

We are still involved in talks with patient groups, pharmaceutical companies European parliament and European commission on this very important and highly emotional debate. Over the year we have attended and influenced the debate at various meetings

"Empowerment of patients and their role at EU level, the informed patient and the sustainability of patient organisations into the future" was one of the conferences where we participated last year.

### ANIMAL TESTING

In the Testing on Animals debate we contributed to the discussions on the Safeguarding Quality Biomedical Research in Europe, with its implications on health, science, jobs and ethics. The directive suggests not to ban animal testing but to use second generation (in captive) breeds. The complication with this is that there aren't that many second generation breeds, hence this might lead to the decline in animal testing which will be disastrous to new drug research.

### EUROPEAN PATIENTS' FORUM

ECPP is no longer on the executive board of the European Patients' Forum (EPF) but will continue to collaborate on health issue in Europe.



## MALAWI

2006 has been a busy year of implementation, getting the centres furnished and children registered. It has been a year to get to know the communities we work in. Finding out the problems and learning from the communities on how to solve some of the problems. One major problem is food security caused by lack of rains and inadequate land which leads to poor harvest hence food shortages which directly affects the children. This year was particularly a good year for farming as the rains came in time. Another major problem was lack of school fees for secondary school. Children and especially girl child drop out of school due to lack of fees.

All the centres have different skills training activities which include Tailoring, Knitting, Carpentry, Tinsmith, Pottery, Broom Making, Music, and Sports. The children are encouraged to take part in at least one activity every twelve weeks.



The ECPP office in Malawi continues to support and monitor the smooth-running of all projects and centres.



### CHAMBE CHILDREN'S OASIS

Chambe Rock Children's Oasis has developed into a robust centre with 400 orphans. The centre now has 80 children who attend the nursery centre and are taught how to play and share in groups. The sports team has played football with other centres and this has enabled them to develop and foster

better community relations where children from different communities are learning from one another. The 400 children are provided with one meal a day and have a weekly health check by the ECPP nurse. Chambe Rock was the first centre to record a music CD which promotes awareness of HIV/AIDS in Malawi and how the disease has affected orphans.

### CHIUTA CHILDREN'S OASIS

This centre is well situated near the main road with easy access from Blantyre and supports 288 orphaned children. The building has been equipped to provide life skills activities and provide the children with one meal a day. Some of the activities run here are: tailoring, knitting, music & drama, carpentry, tinsmith and sports. This is the only centre with an upright piano which the children enjoy playing and there is a growing number of girls learning to play musical instruments.



## ST THERESA UNDER FIVES CHILDREN'S OASIS

St Theresa's Under Fives Children's Oasis continues to be used as a day nursery equipped with toys and books. 110 children are now cared for and fed. The centre is a great support for the community stricken by the epidemic, enabling the carers to carry out their daily tasks without having to worry about the orphans. The children are fed daily with Likuni pala a high protein porridge, they also get soap every month and uniforms every term.



## TITHANDIZANE CHILDREN'S OASIS

ECPP started life skills activities at Tithandizane Children's Oasis. The bore hole and latrines were completed and the centre was equipped with sewing machines & stools, cutting tables and benches. It is providing 950 children with sewing and carpentry skills. The centre aims to provide services for 1,500 children in the future. The chiefs at this centre have had difficulties working together and this has caused friction in the management committee.



## MILANJE CHILDREN'S OASIS

The construction of Milanje Children's Oasis in Mozambique has now been completed which includes two latrines. The centre will

accommodate 650 children from seven villages. The activities planned are tailoring, carpentry, music, piggery and community garden as they have sufficient land.

## TIPEWE CHILDREN'S OASIS

Tipewe Children's Oasis was opened with a kitchen, two latrines and a borehole to provide water. The centre can accommodate a capacity of 400 children and the activities provided are: tailoring, knitting, music and drama, carpentry, tinsmith and feeding. It is important that the children learn some farming skills therefore a vegetable garden has started and this year they harvested 6 bags of maize. In addition to ensuring the sustainability of the centre piggery will be started as there is ample land.



## UGANDA

Ongoing conflicts in northern and eastern Uganda have resulted in limited access to basic healthcare, with unqualified health personnel serving the vast majority of the population.

Signs of social breakdown in the camps include high levels of promiscuity, girls opting for early marriages, and an increase in the number of child mothers. With no schooling and no income-generating activities to occupy them, youths in the camps have become idle, left to self-destructive practices like drinking, unprotected sex, and early marriages.



ECPP has worked in partnership with local communities and faith based organisations that work with orphans.

Due to the ongoing insecurity in the region it has been difficult for any intervention to be fully implemented and sustained hence leaving gaps in service provision and access. The mostly affected group has been the youth.

This year, peace talks between the government and the rebel group have commenced and there is hope that this will

bring stability in the area and services can then be delivered to the people who most need them.

ECPP has been working with the NUSAF agency in setting up two pilot centres in Gulu and Nebbi, where a total target number of 400 youths between the ages of 10-19 have been identified for care and support.

ECPP has developed a strategy for working with identified partners these include the local community based organisations (CBOs) already working with children/youths in the districts in identifying the vulnerable youths and ensuring non-duplication of services and efficient use of limited resources.

In 2006 we started a treatment programme for people living with HIV/AIDS.



This programme was designed to provide ARV for the clinics in these districts, however these clinics are in the rural areas and have poor access and due to insecurity in the area it has been difficult to ensure that the targeted group gets all the services.