EATG
EUROPEAN AIDS TREATMENT GROUP

Annual report 2011

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Content

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LIST OF ABBREVIATIONS

A&M	AIDS & Mobility
ARV	Antiretroviral
ATAC	AIDS Treatment Activists Coalition
BBID	Blood Borne Infection Diseases
BOD	Board of Directors
CAB	Community Advisory Board
CHMP	Committee for Medicinal Products for Human Use
COPE	COntinuous Patient Education
CSF	Civil Society Forum
CTAC	Canadian Treatment Action Council
ECAB	European Community Advisory Board
ECDC	European Centre for Disease prevention and Control
EHRN	Eurasian Harm Reduction Network
EMA	European Medicines Agency
ENVI	Committee for Environment, Public Health and Food Safety
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
FDA	US Food and Drug Administration
FEMP	Future of MSM Prevention
H-CAB	Hepatitis Community Advisory Board
IDU	Intravenous Drug User
MEP	Member of the European Parliament
MSF	Médecins sans Frontières
MSM	Men who have Sex with Men
MTAB	Master Toolkit Advisory Board
NeLP	Network of Low Prevalence countries
NNRTI	Non-Nucleoside Reverse Transcriptase Inhibitor
PCWP	Patient and Consumer Working Party
PDCO	Paediatric Committee
PLWH	People Living With HIV/AIDS
PWG	Policy Working Group
R&D	Research & Development
S&T	Science & Technology
TAG	Treatment Action Group
UA	Universal Access
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNODC	United Nations Office on Drugs and Crime
WCAB	World Community Advisory Board
WHO	World Health Organisation

"We protect and promote human rights in our work."

I. IMPROVE AIDS POLICY AT EU/INTERNATIONAL LEVEL

1.1. The Policy Working Group (PWG)

Chairs: Raminta Stuikyte, Peter Wiessner (since second half 2010)
Policy Adviser: Nicole Heine (until December 2011)

EATG PWG members provide input through their membership in the Policy Working Group, as well as through external bodies like the UNAIDS Programme Coordination Board, UNAIDS Reference Group on HIV and Human Rights, EC Civil Society Forums on HIV and on Drugs, ECDC and Dublin Declaration Advisory Groups, WHO Europe Health in Prison Project Network, the European Public Health Alliance and other.

The Policy Working Group (PWG) membership increased considerably in 2011 from 44 members in 2010 to 57 members in 2011. In order to facilitate collaboration of the group and empower PWG members, the Group started to structure its work, and in 2011 based it on the following three portfolios[1]:

- Men having Sex with Men (MSM),
- Human Rights,
- Access to treatment and care

1.2 EATG puts universal access to ARVs on the political agenda with special focus on quality treatment and care and affordable pricing, in the EU member states and Central/ Eastern Europe and Central Asia

Policy statements and policy-related projects originate from within the PWG and are developed further in discussion groups. In 2011, the PWG produced a draft **discussion paper on access and innovation**[2] which laid the groundwork for a new position paper to be finalized in 2012. Furthermore, EATG provided feed-back to a consultation on the Clinical Trials Directive[3], along with the BOD provided input to the new WHO European Action Plan for HIV, new ECDC testing guidelines and EMCDDA/ECDC document on IDU.

In 2011, four new project proposals were developed by the group:

- two on **low prevalence countries** to address rights and treatment access issues
- one on the organisation of **policy dialogue meetings** and
- one on **Improving access to HIV treatment in Europe and Central Asia 2011**: procurement, pricing and funding

The last two proposals did not receive funding, therefore The PWG worked on improving synergies with EATG's capacity building work[4].

HIV in Europe initiative - early diagnosis and early care
The HIV in Europe initiative is a pan-European initiative kicked off in Brussels in 2007 to ensure that HIV positive patients enter care earlier in the course of their infection than is currently the case, as well as to study the decrease in the proportion of HIV positive persons presenting late for care. The initiative is directed by an independent group of experts with representation from civil society, policy makers, health professionals and European public health institutions. The EATG serves as its Advocacy Secretariat[5].

Building on the momentum ensued since the adoption of the European Parliament 'Joint Resolution on HIV/AIDS: early diagnosis and early care', the renewed HIV in Europe 'call to action' (2010-2011) and national developments, the EATG HIV in Europe Advocacy Secretariat advocated for earlier diagnosis and earlier care seeking to reinforce political commitment and action at national and European levels.

1 In line with objective 1.2.3 of the 2011 workplan: EATG continues its work centred around vulnerable groups (MSM, IDU, migrants)
2 In line with objective 1.1.1: EATG develops and promotes a position paper on **access and innovation** and objective 7.3.2: ECAB and PWG strengthen their collaboration on cross-cutting issues
3 In line with objective 1.1.10: EATG monitors the development of EU directives
4 In line with objective 8.1.4: EATG increases members' capacity to deliver training programs inside EATG
5 In line with objective 1.1.4: EATG continues to hold the political secretariat of the HIV in Europe initiative

More specifically, in 2011 this involved:

- Advocating for an own initiative report on the EU communication on HIV/AIDS in the neighbouring countries (2009-2013)
- Advocating to have the Environment, Public Health and Food Safety (ENVI) committee in the European Parliament prioritise an EP resolution relating to the EU communication on HIV/AIDS in the neighbouring countries (2009-2013)
- Engaging Members of the renewed European Parliament on HIV/AIDS in general and in particular on HIV early diagnosis and early care (i.e. collaborate on Parliamentary Questions to the ENVI committee)
- Advocating for EU Council Conclusions under the EU Presidencies (Spanish Presidency, Belgium Presidency). Various meetings with EU Presidency representatives, seeking engagement of key opinion leaders in the field)
- Engaging the Think Tank and EU Civil Society Forum in issues relating to early diagnosis and early care
- Representing the HIV in Europe initiative Steering Committee at conferences (HIV in European Region – Unity and Diversity, Tallinn, May 25-27 and HIV in Portugal Conference, Lisbon, September 30)
- Recommending an article in the Parliament Magazine highlighting the HIV in Europe initiative in the HIV special issue of 2011
- Drafting press releases for HIV in Europe initiative and providing input to grant applications.
- Input to the HIV in Europe Copenhagen March 2012 conference programme

Early 2011 the initiative reinforced its commitment to implement its projects in Eastern European countries. The stigma index project builds on data from Estonia, Moldova, Poland, Turkey and Ukraine. 40% of persons enrolled into the HIV Indicator Diseases across Europe Study (HIDES I) project are from Eastern European countries. The newly approved HIV-COBATEST project will be implemented in Eastern Europe.

During the European Conference «HIV in European Region - Unity and Diversity» that took place 25 - 27 May 2011 in Tallinn, Estonia, results of the stigma-index report were presented and the results disseminated by a press-release. The HIV in Europe Steering Committee in collaboration with WHO Europe is currently discussing the possibility of organising a conference in Eastern Europe in 2012-2013 on testing, to discuss barriers to testing from an Eastern European perspective.

In 2011, EATG participated in two face-to-face HIV in Europe Steering Committee meetings and two stakeholder meetings. For more information on the initiative visit http://www.hiveurope.eu/

EATG has provided input into the finalization of the CSF/HIV position on drug policy and presented it at the World AIDS Day event in the European Parliament that was organized by ECDC and EMCDDA[6]. In 2011, the EATG was selected to join the other CSF, on drugs. The Forum on drugs started drafting its recommendation on the new EU drugs policy and the EATG is actively participating in that process which is to conclude in 2012.

1.3 EATG puts human rights of PLWH and vulnerable groups on the political agenda

In preparation to future activities and debates on the subject in 2011, EATG Policy Working Group Chairs Peter Wiessner and Raminta Stuikyte released a discussion paper 'Does it matter which ministry is responsible for health in prison?' calling for shifting responsibility for health of people in closed settings to the ministry of health. EATG continued updating the database on HIV-related travel restric-

6 In line with objective 1.1.9: EATG provides input to the upcoming consultation on the EU drugs strategy (first quarter 2011) and promotes the CSF position on drug policies once finalised

tions. Its review covering Eastern Europe and Central Asia was noted by the UNDP's supported Global HIV and Law Commission[7].

EATG in Correlation Network II: HIV policy for rights and needs of key populations

EATG continued its involvement in the Correlation project[8] which aims to tackle health inequalities, and to improve prevention, care and treatment services, targeting blood borne infection diseases (BBID's), in particular HIV/AIDS and Hepatitis C among vulnerable and high risk populations. Main funding for the Network was provided by the European Commission.

The EATG took the lead on the network's HIV component uniting various organisations and advocates for HIV policy recommendations for 4 vulnerable groups within the project: injecting drug users (IDU), sex workers, men who have sex with men (MSM) and migrant populations. It performed a literature review of existing recommendations. With the PWG support a survey was prepared and launched to assess the implementation of HIV/AIDS policies across Europe from a practitioner's point of view. The Policy Recommendations were finalized in the second half of 2011.

For more information about the Correlation II project, visit http://www.correlation-net.org/

• Correlation Network policy seminar – 29-30 June 2011 in Brussels

EATG organized a Correlation Network Policy Seminar called 'Breaking the barriers, bridging the gaps: Health inequalities, the HIV/AIDS response and political leadership in the European Union'[9]. This meeting provided the opportunity to present and discuss the Correlation draft policy recommendations on HIV/AIDS – and to engage policy makers to address priority issues identified and representatives of the HIV and harm reduction communities from across Europe in joint advocacy activities.

During the first part of the seminar, an introduction to 'EU policy making and public health and HIV related processes at EU level' was given, and participants identified upcoming advocacy opportunities. Furthermore, participants strategized on how to best raise their concerns during the second part of the seminar in the European Parliament.

The recommendations were presented during the second part of the seminar. This part took place in the European Parliament in Brussels and hosted by

Marisa Matias and Elisa Ferreira, both Members of the European Parliament and opened by Michael Cashman and Antonyia Parvanova. Speakers included representatives from the European Commission (DG Sanco and DG Justice), the European Centre for Disease Prevention and Control (ECDC), the EU HIV/AIDS Civil Society Forum (CSF), National HIV/AIDS coordinators (Poland, Portugal, and Denmark), Correlation partners, and community members of affected groups as well as harm reduction and public health community representatives.

7 In line with objective 1.1.7: EATG promotes prisoner's health and in particular access to HIV "through care"
8 In line with objective 1.2.1: EATG produces and disseminates policy recommendations for 4 vulnerable groups within the context of the Correlation project
9 In line with objective 1.2.2: EATG organizes a policy dialogue meeting in the EP to present the Correlation policy recommendations project and raises awareness on vulnerable groups

10 In line with objective 1.1.2: EATG continues engaging the European Parliament (EP) on HIV/AIDS related issues by organizing one interparty EP conference (Correlation Policy Summit); advocating for an EP own initiative report or a WAD resolution in response to the EU Communication on HIV/AIDS; initiating together with partners 2 MEP hosted lunch debates

11 In line with objective 1.2.3: EATG continues its work centred around vulnerable groups (MSM, IDU, migrants)

12 In line with objective 1.2.5: EATG continues to support the EU HIV/AIDS Civil Society Forum as part of the CSF coordination team

The seminar concluded with a discussion on how to turn the recommendations from the Correlation project into action. This meeting was also the opportunity to explore the interest in organising a MEP intergroup on HIV in the future. It was decided that steps would be taken to investigate the need for such an intergroup[10].

- **Final conference Correlation- 12-14 December 2011, Ljubljana, Slovenia**

EATG organised a session on HIV/AIDS policy during the final Correlation conference. The session was chaired by both Wolfgang Philipp from the European Commission, DG Sanco and Martine De Schutter, representing AIDS Action Europe and the Civil Society Forum on HIV/AIDS. The focus of this session was the presentation of the ten Policy Recommendations that have been developed within the framework of the project. These recommendations have been developed to inform policy making in Europe, both at national and EU level. The recommendations call on governments to ratify and live up to the existing conventions and norms embedded therein, focus on upholding and safeguarding the human rights of populations most affected by HIV. The speakers discussed how these recommendations can help civil society to create a change by providing guiding principles for national responses and to stimulate national collaboration.

Within a session called 'A focused response to HIV in Europe: setting up policy recommendations to tackle health inequalities in Europe' Bryan Teixeira presented the 10 recommendations on vulnerable groups such as migrants, MSM, IDU and sex workers that have been developed[11]. A second session 'Making a difference – civil society and the HIV response (panel discussion)' was presented by Ninoslav Mladenovic to discuss how to translate the recommendations and other guidelines to a national/regional level. One of the good examples he shares with the audience is the recent establishment of the Network of Low Prevalence Countries (NeLP).

EU HIV/AIDS Civil Society Forum (CSF) and EATG Policy Projects

- **The EU HIV/AIDS Civil Society Forum (co-chairs on behalf of EATG: Luis Mendão from May 2010 until June 2011, Anna Żakowicz from June 2011)**

EATG is co-chairing the EU HIV/AIDS Civil Society Forum (CSF) which has been established by the European Commission as an informal working group to facilitate the participation of non-governmental organizations, including those representing people living with HIV/AIDS in policy development and implementation and in information-exchange activities[12]. The CSF includes about 40 organizations from all over Europe. AIDS Action Europe (AAE) and EATG co-chair and provide support to the work of the EU HIV/AIDS Civil Society Forum, an informal advisory body to the European Commission.

Standing agenda items at CSF meetings include updates from DG for

Health and Consumers of the Commission (DG Sanco), the European Centre for Disease Prevention and Control (ECDC), the World Health Organisation Regional Office Europe (WHO Europe), the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the European Monitoring Centre for Drugs and Drug Addition (EMCDDA) as well as reports on the EU Presidencies work on HIV/AIDS.

In 2011, 2 meetings took place (27-28 June, 6-7 December 2011).
Agenda items of the meetings included:

- Protecting HIV services during times of budgetary cutbacks
  Joining forces to fight criminalization of HIV
- Current situation in Ukraine around ART and substitution treatment
- Impact of financial cuts on drugs access and prescription
- Prison Health: Council recommendations
- National Danish study on late presenters
- Preliminary results from the European MSM Internet Survey 2010
- Leveraging the political momentum of the High Level Meeting for a renewed and strengthened EU response to AIDS

Throughout 2010-2011, the CSF engaged in advocacy on the on-going legislative work relating to the Equality Directive[13], Council Conclusions on HIV/AIDS, 'HIV/AIDS own initiative report' by the European Parliament, input to high-level speeches at the World AIDS Conference, travel restrictions relating on HIV/AIDS in the EU, EU Free Trade Agreement negotiations as well as ARV treatment stock-outs occurring in several European countries and putting HIV high on EU presidency agendas, including the upcoming Danish Presidency on HIV/AIDS.

An oral question to the Commission on the state of implementation of the EU Communication on combating HIV/AIDS (2009-2013) was discussed in the Committee for Environment, Public Health and Food Safety (ENVI). The ENVI committee coordinators decided that **a discussion on HIV/AIDS take place in the plenary of the European Parliament around World AIDS Day 2011,** and might decide to adopt a resolution on HIV/AIDS focussing on the EU and neighbouring countries.

The Danish Presidency was asked to have HIV/AIDS figure in their presidency programme[14], by having an HIV in Europe conference during the Danish Presidency (March 12-13 2012, Copenhagen) taking place under the auspices of the Danish Presidency. **The Danish Minister of Health agreed and confirmed high level political support from his ministry to the conference.**

One of the main achievements was the adoption of a CSF statement on drug policies in May 2011. The statement argued the case for putting health considerations in drug policies first, and was issued timely before the process on the new EU drug policy strategy consultations started. During its June 2011 meeting, the CSF decided to work on a statement fleshing out principles that should govern decision making processes as to changes in treatment regimens at times of budgetary constraints.

13 In line with objective 1.1.10: EATG monitors the development of EU directives
14 In line with objective 1.2.6: EATG collaborates with upcoming EU presidencies seeking to put HIV related topics on their political agenda

15 In line with objective 1.1.8: EATG promotes HIV treatment and human rights challenges and supports its national partners in its 2 PWG meetings organized in selected countries/regions, in collaboration with local partners
16 In line with objective 1.2.8: EATG continues its efforts to counteract human right's violations, stigma and discrimination of PLWHA
17 In line with objective 1.1.3: EATG continues its work centred around pricing issues

• Policy Working Group meetings

In February 2011, the first Policy Dialogue Meeting took place (Riga, Latvia, 19-21 Feb 2011). The meeting followed up on previous in-depth discussions of the PWG about the Latvian, Estonian and Lithuanian situation as to HIV/AIDS and in particular as follow up on the 2009 and 2010 WHO/UNODC country visit reports[15].

The objectives of the meeting were to:
- learn from local community organisations and invited experts on what has happened in Latvia since 2009 to address issues identified in the WHO UNODC report
- take stock of the current access to ARV, co-infection treatments and drug policies
- identify cross-cutting policy issues as to access to HIV/AIDS treatment and care in the Baltic states
- facilitate networking within the HIV community but also with local authorities and other relevant institutions to achieve universal access in the Baltic region
- strategize as to how local community organisations, EATG and other networks could join forces to improve the situation by working nationally and at European level
- Create a clear consensus on strengthening EATGs work strand on prison health and on the need to engage the European Parliament on the subject emerged.

Region-specific agenda items comprised
- Background to the situation in Baltic
- Harm reduction services in the Baltics
- Prisons: situation in the Baltics and beyond[16]
- Hepatitis C – Access in Latvia and policy work in the region (and Europe)
- Latvia, Lithuanian and Estonian partner organisations: presentation of their organisations, work and main concerns (AGIHAS, ENP, Pozityvus Gyvenimas)
- Taking stock – what happened since 2009 from a Latvian/Lithuanian/Estonian community perspective (including some information on the impact of the economic crisis)
- ARV pricing[17] and ARV procurement: towards a Baltic agreement on pooled procurement of medicines

As part of the series of Policy Dialogue Meetings, the Hungarian Civil Liberties Union (HCLU) supported by the EATG PWG organized a **Budapest meeting on the situation in low prevalence countries** (25-27 June, 2011): http://tasz.hu/en/east-east/network-low-hiv-prevalence-countries-central-and-southeast-europe-nelp-policy-meeting.

The aim of the meeting was to discuss the need to set up a network of low-prevalence countries in the region and to draft a declaration on minimum standards of care, treatment and prevention and reform of legislation ('Budapest Declaration'). Participants drafted the Budapest Declaration which was launched on September 1, 2011. Items on the agenda included

- Low-prevalence and regional issues – a need for a network
- Legislation and key populations
- Care, treatment and prevention (minimum standards)
- Introduction and workshop session 1 (minimum standards of prevention, treatment and care)
- Workshop session 2 (legislation and policies)
- Workshop session 3 (key populations)
- Future plans and tasks – the sustainability of the network

A **second Policy Dialogue Meeting** took place in Belgrade, Serbia (11 October 2011) prior to the European AIDS Clinical Society (EACS) Conference[18]. Building on the results of the Budapest meeting, the meetings will focus on how to address the problems delineated in the Budapest Declaration. During this meeting the Network of Low Prevalence countries (NeLP) was officially launched. People were requested to sign the Budapest Declaration.

A website was developed by the Hungarian Civil Liberties Union (www.nelp-hiv.org). People have done translations of the declaration into 9 local languages. There are 11 of 16 country profiles posted.

On Friday November 4, a **third Policy Dialogue meeting** was organised prior to an internal policy meeting to discuss the causes of involuntary treatment interruptions in Romania that have affected over 60% of people living with HIV (PLWH) on HIV treatment since 2009 and actions that could be taken to prevent their continuation[19]. The meeting was attended by 20 community representatives (members of EATG and local organisations) and 12 representatives from the Romanian government, other institutions and medical community. In the meeting we took stock of the current access to ARV, co-infection treatments and drug policy in Eastern Europe and identified areas of collaboration with EATG in 2011-2012. We discussed with local partners how to best use the emergency guidelines developed by EATG for the case of involuntary treatment interruption and identified further partners for our joint work.

Working with the European Parliament

EATG collaborates with Members of the European Parliament on a whole range of HIV related issues. In order to ensure HIV remains high on the agenda of the European Parliament, first steps were taken to establish an informal cross-party intergroup of MEPs at the European Parliament working on HIV/AIDS related issues in Europe and the neighbouring countries[20].

EATG members spoke on various occasions at EP events. During the EP conference 'Can we afford the current model of innovation: towards new models of innovation', Policy Working Group Co-chair Raminta Stuikyte spoke about 'Access to pharmaceuticals in Eastern Europe'. Furthermore, EATG provided input to the programme of the European Parliament hearing of the Human Rights Committee on World AIDS Day.

On April 13 2011, together with the Secretariat of the European Parliament Working Group on Innovation, Access to Medicines and Poverty-Related Dis-

18 In line with objective 1.2.7: EATG organizes a one day meeting on the situation of low prevalence countries in Belgrade/Serbia identifying key problems in the region, map the situation and focus on the implementation of the Budapest declaration (October 2011) (prior to the EACS conference)

19 In line with objective 1.1.5: EATG continuously monitors and raises awareness on ARV treatment interruptions throughout the EU, as well as in the Balkans, Eastern Europe and Central Asia

20 In line with objective 1.1.2: EATG continues engaging the European Parliament (EP) on HIV/AIDS related issues by organizing one interparty EP conference (Correlation Policy Summit); advocating for an EP own initiative report or a WAD resolution in response to the EU Communication on HIV/AIDS; initiating together with partners 2 MEP hosted lunch debates

eases, a roundtable was organized at the European Parliament last on Drug-resistant TB and TB-HIV co-infection on the EU's doorstep with the example of Ukraine. Two MEPs from the EU-Ukraine Parliamentary Delegation opened the roundtable, followed by presentations of WHO Europe, the International HIV/AIDS Alliance Ukraine, MSF and the European External Action Service (former DG RELEX of the European Commission). The meeting resulted in the inclusion of TB and HIV in the discussions of the next EU-Ukraine Parliamentary Cooperation Committee that was held in Kyiv in November 2011. Civil society organisations and WHO Europe were invited to present the current situation.

AIDS 2011 "HIV in the European Region – Unity and diversity", 25 - 27 May 2011, Tallinn, Estonia

EATG participated through some of its members in the conference "HIV in European region – unity and diversity", held in Tallinn, Estonia from 25 to 27 May 2011. Anna Żakowicz, Raminta Stuikyte, Peter Wiessner, Svilen Konov, Roman Dudnik, Igor Sobolev, Konstantin Lezhentsev, Nikos Dedes and Anastasia Solovyeva took the floor in plenary and/or parallel sessions among policy-makers, public health administrators and representatives from non-governmental, international and community based organisations to express the situation, the progress and the needs in the European region against the spread of HIV.

Policy Working Group membership

The Policy Working Group currently has 61 members from 32 countries: Albania; Armenia; Austria; Belarus; Belgium; Bulgaria; Croatia; Denmark; Estonia; Finland; France; Germany; Greece; Hungary; Ireland; Israel; Italy; Kyrgyzstan; Lithuania; Macedonia; Netherlands; Portugal; Romania; Russian Federation; Serbia; Spain; Switzerland; Tajikistan; Turkey; Ukraine; United Kingdom; Uzbekistan. Almost half of the members are from Central or Eastern Europe (25 out of 61)[21].

21 In line with objective 4.1.4: The PWG continues reaching out to the East by diversifying its membership to reach appropriate representation of populations and countries with a high burden of disease

"To perform its activities and to reach its goals, the EATG works closely together with many different actors on the field."

II. PROMOTE TREATMENT PREPAREDNESS AND BUILD CAPACITY

2.1 The trainers' pool, our trainings and educational materials

Training coordinator: Ana Lucia Cardoso

Capacity building is a continuous process at EATG. One important part of our work in 2011 was the development and distribution of educational materials, training design and delivery in South Eastern Europe and Eastern Europe.

Our pool of trainers supported by the training coordinator organise several training activities per year. The trainers contribute to the development of a continued training strategy for EATG and deliver training sessions in different meetings across Europe. Our objective is to develop treatment knowledge of the community as well as their skills to advocate for access to HIV/AIDS treatment in their countries. Ultimately, we would like participants to become trainers in their countries and to support us in strengthening the capacity of the communities locally.

During the trainings educational material is distributed including our manual on treatment literacy and advocacy[22]. An update is planned in 2012-2013.

Through our training activities we aim to reach as many people living with HIV/AIDS as possible, their health care providers, civil society representatives and everybody working in the field and advocating for Universal Access to HIV/AIDS prevention, treatment and care.

The following examples illustrate the variety of capacity building initiatives developed by the EATG and its trainers in 2011.

Training 1) HIV/AIDS Treatment Literacy and Advocacy, Bucharest, Romania, 8-18 July, sponsored by Bristol-Myers Squibb (BMS) and in partnership with Senz Positiv Romania

Training was organised for participants from South Eastern Europe: Romania, Bulgaria, Croatia, Montenegro, Macedonia, Albania, Kosovo, Serbia, Turkey and Greece. We received 32 applications and 18 participants attended the training[23].

The working groups focused on the following issues for their advocacy plans: procurement of treatment and regular monitoring tests; involving the patient community in collecting reliable data for evidence based research; tackle stigma and discrimination, considering people with disabilities and the most at risk groups; building capacity of doctors, health practitioners, PLWH and their supporters.

The training included a study visit to a methadone and drop in centre in Bucharest. Our Policy Working Group followed up with the advocates from the region by organising a Policy Dialogue Meeting to discuss the causes of involuntary treatment interruptions in Romania (see page 10).

Trainers: Deniz Gokengin, Ninoslav Mladenovic, Romy Mathys, Tamás Bereczky, Tomislav Vurusic

Training 2) HIV/AIDS Treatment Literacy, Kiev, Ukraine, October 27-30, sponsored by Sidaction and in partnership with the All-Ukrainian Network of People Living with HIV

With financial support from the French organisation Sidaction, EATG is developing a project entitled: "Empowering the HIV Community in the East to promote Universal Access (UA) to prevention, treatment, care and support - HIV/AIDS Treatment Literacy Training for the Ukrainian Community of PLWH and their health care providers" As part of the project, the EATG with the All Ukrainian Network OF PLWH organised a meeting for community groups, service providers, treatment counsellors and health care providers

22 In line with objective 2.2.3: EATG updates, prints and further distributed its manuals on treatment literacy and advocacy

23 In line with objective 2.2.1: EATG identifies training needs across Europe and develops the concept of a Training Centre

who care for HIV+ patients in Ukraine, Belarus and Moldova[24].

The goal of the training was to increase the level of knowledge of participants on HIV/AIDS treatment, co-infections with TB and Hep C, advocacy for access to treatment, as well as to exchange best practices from different countries and strengthen the relationship between community and health care providers. For this reason, a multisectorial approach was used when selecting the participants, encouraging both activists and medical workers to participate in the training.

The agenda of the training included topics such as 'History of HIV treatment activism'; 'Introduction to Combination Therapy'; 'Human rights as a Framework'; 'Care for injecting drug users'; 'Tuberculosis', 'Hepatitis C', 'Clinical trials' and 'Advocacy in Ukraine'.

Trainers: Alain Volny-Anne, Alexander Urchenko, Anna Żakowicz, Denis Godlevskiy, Dmitry Sherembeyi, Stephan Dressler, Svilen Konov

2.2 EATG further identifies its position in the training field

A first **trainers pre-meeting** was organised in **Brussels, 9-10 April 2011.** The objective of the meeting was to discuss content and programme for 2011 trainings, manuals update and distribution. The group also discussed future training needs and projects, EATG training work plan and strategy. The concept for a Training Centre was also discussed[25].

Following an Open Call for the membership EATG recruited Romy Mathys and Tamás Bereczky as new trainers.
Regarding the future training strategy we should aim at:

- Ensure continuity/sustainability of trainings: minimum of 2-4 trainings/year
- Half trainings focusing on region, other half on key population – ensure diversity in target audience and region
- Ensure internal training for members and in particular for new members
- Increase visibility of EATG trainings

During our 2011 General Assembly our members discussed the long-term strategy for our capacity building activities for 2012-2015 that should be two-fold:

1. Strengthening the advocacy capacity of the HIV community in Europe in matters relating to access to treatment
2. Engaging the membership in understanding and supporting the work of the EATG.

In the end of 2011 our members requested our Training Coordinator and Executive Director to develop a market study and project plan for the legal establishment of an EATG Training Centre. This is to be presented and discussed at the 2012 General Assembly[26].

24 In line with objective 2.2.1: EATG delivers trainings on treatment literacy and advocacy
25 In line with objective 2.1.1: EATG consolidates its trainers/capacity building taskforce to advise on development of continued training strategy for the organisation, to contribute to development and distribution of training materials, to account for contribution of community organisations to HIV capacity building across Europe and to deliver trainings/train the trainers activities across Europe
26 In line with objective 2.1.2: EATG identifies training needs across Europe and develops the concept of a Training Centre

2.3 EATG builds partnerships with other capacity building initiatives and training centres

Aids&Mobility Europe 2007-2010

- The AIDS & Mobility Europe 2008-2011 Master toolkit

The A&M project, active in various European countries, builds on the AIDS & Mobility Europe network founded in 1993 and focuses on innovative approaches for HIV prevention among migrant communities. The second phase of the project reached its end in 2011.

EATG was leading the networking activities of the network and developed the Master Toolkit of the project. Since 2008, we organised and evaluated the input from a Master Toolkit Advisory Board (MTAB), a group of experts in the field of migration health that shared experiences and advised on tools and best practice examples on health education. Over the years the feedbacks were collected and taken into consideration for the production of the Toolkit.

Members of the Master Toolkit Advisory Board: Ahmet Kimil, Ana Lucia Cardoso, Bryan Teixeira, Eberhard Schatz, Iris Shiripinda, Jolanta Bilinska, Katrin Schiffer, Maria Jose Peiro, Martin Muller, Matthias Wentzlaff-Eggebert, Mike Hiiza, Ramazan Salman, Matthias Wienold

3rd MTAB meeting - Brussels, 28th March 2011

The third and final meeting of the A&M Advisory Board took place in Brussels, March 28. The group has made final decisions on the composition and format of the toolkit entitled "Let's speak about HIV in our language". Issues related to communication, distribution and update of the toolkit were also discussed.

In September 2011 the Master Toolkit was distributed to members and stakeholders[27]. The toolkit gathers core training materials and relevant additional information from the fields of HIV prevention and migrant health that the project partners consider essential sources for anyone interested in learning about or implementing a transcultural HIV and AIDS mediator project.

The toolkit contains four main packages of materials:

A&M Background Materials - The A&M background materials give an overview of HIV and AIDS and migration. They include case studies, country reports, research and policy documents. A&M Core Training Materials - The core training materials are practical tools that can be used to train transcultural mediators, reach your key populations, and for evaluating your project. They include a training curriculum, slide kits, the AIDS & Mobility Guidebook and evaluation forms. Most are available in a range of languages, representing the cultural groups who participated in the pilot project.

A&M Promotional Materials - The set of promotional materials to show how project partners recruited candidates for mediator training and participants for community information sessions. Supplementary Materials - The last package of materials contains a selection of models and materials that use similar principles and methods or have similar goals to the transcultural mediator model.

The materials can be downloaded from our website: http://www.eatg.org/eatg/Capacity-Building/Projects/Aids-Mobility-A-M/AIDS-Mobility-Master-Toolkit

CoBaSys: Community based system in HIV treatment

CoBaSys is a 3-year project funded by the African, Caribbean and Pacific Science and Technology Programme. The EATG shares experience on capacity building and fostering community involvement. We provide feedback to the training needs assessment performed among the African partners and we will be in charge of organising training on fundraising and project proposal writing in 2012[28].

27 In line with objective 2.2.4: EATG develops a training toolkit collecting best practice educational tools on prevention and treatment

28 In line with objective 2.2.2: EATG delivers training on specific topics related to HIV treatment as appropriate

The overall objective of the project is to strengthen the integration of the Southern and Eastern African countries into the European science and technology (S&T) framework, focusing specifically on programmes for quality health care with special attention to community based and patient centred approaches to HIV treatment. The main specific objective of the project is the development of stable cooperative networks promoting quality health care system in the field of HIV treatment.

- **Mid-term meeting, 27-29 April 2011, Windhoek, Namibia**

EATG was asked to participate at the mid-term meeting as one of the associated partners. During this second meeting of the project, partners presented the results of the discussions in the Focus Groups organised at regional level. At focus group meetings, members of the community discussed main HIV treatment issues to be presented to national stakeholders at a later stage of the project, and with the objective of strengthening participatory method within the local community.

EATG presented the work of the EATG in general and in particular in capacity building/trainings. We also presented our experience in involving the community in policy and research at European level. One of our tasks at the meeting was to gather the feedback from the different partners on training needs. The University of Helsinki prepared a training needs' assessment and presented results to EATG. We will organise training for the African partners in Brussels in 2012.

More information about Cobasys here: www.cobasys.eu/

2.4 EATG supports the adaptation of reliable patient information into a local context

Continuous Patient Education (COPE)
The Continuous Patient Education Project (COPE) is a mechanism for funding the adaptation, translation, production and dissemination of HIV/AIDS treatment materials[29]. The project is funded by Bristol-Myers Squibb (BMS).

In 2011 COPE was presented at our meetings, trainings and HIV related events. In the same period we have funded the adaptation, translation, printing and distribution of the following publications:

- Eurasian Harm Reduction Network (EHRN): "Guide to Hepatitis B for People Living with HIV" from Treatment Action Group (TAG) into Russian
- Plus and Minus Foundation Bulgaria: "Training manual: HIV/AIDS Treatment Literacy and Treatment Advocacy" from European AIDS Treatment Group (EATG) into Bulgarian
- Charitable Foundation Svecha: "TB and HIV co-infection", "Take steps to control TB when you have HIV", "Tuberculosis: connection between TB and HIV" from WHO into Russian
- Estonian Network of PLWH: "HIV & Hepatitis" from NAM into Estonian and Russian
- Senz Positiv Romania: "ARV treatment" from NAM into Romanian
- HERA – Health Education and Research Centre: "HIV & Sex" from NAM into Macedonian
- Albanian Association of PLWH: "Changing treatment and drug resistance" from iBASE into Albanian
- Latvian Society Association HIV.LV: "Avoiding and Managing Side Effects" from iBASE into Latvian
- Adaptation of several publications: UNAIDS guidance note on HIV and sex work 2009 25 pages; UNAIDS action framework on MSM 2009 30 pages; Protecting drug users UNAIDS 2010 30 pages into a single guidance document: "How to effectively work with most-at-risk populations" into Macedonian[30].

29 In line with objective 2.3.1: EATG continues its support to the translation, printing and dissemination of brochures within the context of the COPE project
30 In line with objective 2.3.2: EATG develops priority activities for the hepatitis portfolio

2.5 Develop capacity and capability of membership and staff

A brief info session for new members about EATG was organised prior to the 2011 General Assembly. Our welcome package was updated and will be annually updated and include the following topics:

- About EATG
- Aims and Values
- Structure and Activities
- Membership and General Assembly
- The Board of Directors
- Working Groups
- Overview of our projects and activities
- Office team
- Other Information: becoming involved, attending EATG meetings, representing EATG, how to communicate

Two members were recruited as trainers after an Open Call was sent to all membership[31]. New EATG members from Eastern Europe were given priority for participation in EATG trainings in line with criteria defined by the training coordinator and trainers' pool.

31 In line with objective 8.1.4: EATG increases members' capacity to deliver training programs inside EATG

"We advocate for the best practices of care and treatment."

III IMPROVE CLINICAL RESEARCH AND DRUG DEVELOPMENT AND ACCESS TP PREVENTION, TREATMENT AND CARE IN THE WHO-EURO REGION

The European Community Advisory Board (ECAB)
ECAB chair: Wim Vandevelde (since May 2009)
EATG Scientific Adviser: Laure Sonnier (Since March 2009)

3.1 EATG provides meaningful community input and perspectives into biomedical research including clinical research and drug development

ECAB meetings

ECAB meets several times a year with the pharmaceutical industry and researchers where, under confidentiality, new advances in drug development and access to treatment in Europe are being discussed with patient advocate experts in clinical research and access issues in the WHO EURO region.

From January to December 2011, 4 ECAB meetings focusing on HIV/AIDS took place. In January, ECAB met with GSK Bio and Abbott, in March with ViiV Healthcare, in May with Gilead and Merck, in June with BMS[32].

The September ECAB was both focused on HIV and HCV pipeline development. We met with Tibotec (HIV), Roche (HCV), Abbott (HCV), and Boehringer-Ingelheim (HIV and HCV).
The November ECAB meeting was a thematic meeting focusing specifically on HCV drug development where we met with Tibotec, Gilead, Merck and BMS.

Finally, a second thematic ECAB took place In December and was focused on tuberculosis.

➔ Thematic ECAB meeting focused on Hepatitis C

On November 18-20, 2011, ECAB organised a thematic ECAB focused on HCV drug development.

On this occasion, the new hepatitis portfolio leaders were confirmed. They are Stanimir Hasurdjiev from Bulgaria and Anastasia Agafonova from Russia. The first draft of the EATG/ECAB hepatitis workplan 2012 was presented by the new hepatitis portfolio leaders and discussed further on this occasion.

The finalised Hepatitis workplan will be presented in May 2012 to EATG stakeholders involved in the Hepatitis field on the occasion of a specific stakeholders meeting devoted to hepatitis topics & activities.

➔ Thematic ECAB meeting focused on Tuberculosis

On December 7-9, 2011- EATG organised a thematic ECAB for Community advocates on TB & HIV confection (treatment, care and research issues).

32 In line with objective 3.1.1: EATG maintains effective dialogue with pharmaceutical companies to provide input into clinical development

The purpose of the meeting was to build on the previous ECAB thematic meeting that took place in March 26&27, 2010, to better inform the European community on possibilities for involvement in HIV+TB treatment care and research advocacy and to build a plan of how to do that more robustly on a European level with partners like TB-specific community organisations, international organisations like WHO and the Stop TB Partnership, EMA and local regulatory bodies and pharmaceutical companies. Further to that, it aimed to increase the capacity of the Community to get involved in TB drugs and diagnostics development and identify key advocacy priorities to further work on.

The training was attended by around 30 patient advocates from EATG/ECAB and other civil society institutions coming from the WHO-53 region. Many Community representatives from Central and Eastern Europe attended the training to help build capacity around TB/HIV treatment, care and research issues in the region. Speakers included patient advocates, clinical researchers, regulatory officers, and international organisation representatives active in the TB research field.

Further information about the event can be found here: http://www.eatg.org/eatg/Scientific-Research/Conferences/Second-Thematic-ECAB-on-Tuberculosis-December-9-11-2011

ECAB / EATG strives to continuously build capacity and strengthen the impact of the group

➔ ECAB organises regular trainings on major HIV research topics

Several trainings also took place from January 2011 to December 2011 during ECAB meetings[33] [34] .

- In January 2011, Svilen Konov organised training on clinical trial design and protocol review together with Michal Odermarsky.
- At the March ECAB meeting, training on HIV genetics and stem cells research was coordinated by Svilen Konov. Dr Gero Huetter from Mannheim University talked about “transplantation and gene therapy in the treatment of HIV infection” and Dr Takis Athanasopoulos from the Royal Holloway University of London presented on “host genetics and HIV: novel gene/cell therapy and genetic vaccine approaches”.
- Finally at June ECAB, training on tropism testing was coordinated by Stephan Dressler. Dr Annemarie Wensing from Utrecht University delivered the training.

➔ ECAB is working on the review and evaluation of the group

ECAB has now secured funding to conduct a review of ECAB. The objective of the research/evaluation project is to review the role and functioning processes of the European Community Advisory Board on HIV/AIDS biomedical research with the objective to evaluate past impact and put forward a set of sound recommendations for the future. The major steps and deliverables that ECAB are currently organising are listed below.

- Research and evaluation :

A consultant will review the role, functioning processes and analyse the impact of ECAB on HIV/AIDS biomedical research. Data will be gathered by means of focus groups, interviews and questionnaire based-survey of relevant stakeholders. This evaluation will inform of the most effective ways of to provide community input in HIV/AIDS biomedical research.

- Production of report and recommendations:

A report of the research with a series of recommendation for the way for-

33 In line with objective 3.1.8: EATG provides continuous training to members and partners on scientific topics

34 In line with objective 8.1.3: EATG builds ECAB capacity by organising regular trainings for ECAB/EATG members on prominent HIV research topics

ward will be produced and disseminated widely to community partners and relevant identified stakeholders

- Public presentation of report and recommendations:

The outcome of evaluation (report and recommendations) will be shared and discussed further with a wider appropriate audience during a multi-stakeholder public meeting. 1-day event attached to an ECAB meeting in Brussels.

We are now finalising the ToR for the consultant and structuring the methodology of the project.

Community reviews of clinical research protocols

An important expertise of ECAB is to review clinical trial protocols and informed consent sheets from the PLWHA Community's perspective and needs. In 2011, ECAB reviewed 4 clinical trial protocols and 1 informed consent forms from different pharmaceutical companies and research institutions. The main protocol inputs were taken into account by the trial sponsors and the protocols and ICFs were adapted accordingly.

Participation in HIV scientific projects and Networks

ECAB members were involved in numerous scientific HIV projects and networks. We mention a few:

➔ NEAT (European AIDS Treatment Network)

Nikos Dedes, steering committee member & NEAT project leader for EATG

http://www.neat-noe.org

EATG is the community partner of the European AIDS Treatment Network (NEAT), the EC Network of Excellence which is a platform for Academic HIV Clinical Research[35].

The main deliverables of NEAT are centred around clinical research, among which the NEAT001/ANRS143 HIV clinical trial is a strategic trial investigating two different treatment combinations to treat HIV-1 infected patients that have never been treated for their HIV infection before. It compares a standard regimen of three drugs that are already recommended as first-line therapy (regimen for treatment naïve HIV-1 patients) to an innovative treatment option that combines two potent recent antiretroviral drugs. A second important deliverable of NEAT is the creation of the Hepatitis Cohort Network (a network including the major experts in the field of HIV / HCV coinfection) that is looking into setting up a cohort of patients for the PRospective OBservational Evaluation (PROBE) study on the natural history and treatment of acute HCV in HIV positive individuals in Europe.

NEAT was planned to end in January 2012 but following the NEAT annual General Assembly that took place in May 2011 in Rome it was announced to partners that a no-cost extension for 18 months had been granted by the EC in order for partners to finalise all agreed activities (especially the NEAT 001 trial). The EC will not continue to fund the consortium after this extension period and the future of the consortium after completion is thus unclear.

➔ EUROPRISE

David Haerry, steering committee member & Europrise project leader for EATG

www.europrise.org

Europrise is a Network of Excellence funded by the European Commission under FP6, which aims to bring together EU scientists from both microbicide and vaccine fields to embrace a coordinated approach to HIV-1 prevention research[36].

35 In line with objective 3.1.3: ECAB continues its engagement within the NEAT project

36 In line with objective 3.1.4: EATG continues its engagement within the Europrise project

On July 17th, 2011, during the 6th IAS conference on HIV pathogenesis, treatment and prevention, in Rome, EATG organised the satellite meeting: "Controlling the epidemic: the promise of ARV-based prevention"[37].

The satellite was hosted together by AVAC, EATG and the Forum for HIV Collaborative Research funded by Europrise. The objective of the satellite was to discuss issues in development of large-scale community based prevention pilots. The meeting and discussion argued the case for making HIV epidemic control the goal of prevention, for assembling the required expertise and deploying essential resources, to conduct needed studies.

We secured participation of renowned speakers in the field: Gus Cairns, EATG/NAM; Victor DeGruttola, Harvard University School of Public Health; Matthias Egger, University of Bern; Kevin Fisher, AVAC; David Haerry, EATG; Tim Hallett, Imperial College; Catherine Hankins, UNAIDS; Sheena McCormack, UK Medical Research Council; Veronica Miller, Forum for Collaborative HIV Research; Jim Rooney, Gilead; Mika Salminen, ECDC; Robin Shattock, Imperial College; and Pietro Vernazza, Swiss National AIDS Commission.

The satellite was a great success, attended by a large audience of researchers, clinicians, community advocates, representatives of international organisations and civil society. It came at a timely moment as the results of both the Caprisa and HPTN 052 trials had become available at the time which was a strong focus of the IAS conference. The satellite was a perfect introduction for the discussions that then took place during IAS on treatment as prevention and all the challenges linked to it.

All information about the IAS satellite is available at:
http://www.eatg.org/eatg/Scientific-Research/Conferences/Controlling-the-HIV-epidemic-The-promise-of-ARV-based-prevention

➔ CHAARM (Combined Highly Active Anti-Retroviral Microbicides)

Gus Cairns, steering committee member- David Haerry- EATG leader for CHAARM

CHAARM is a research network funded by the EC under FP7 that looks into developing combinations of new and existing microbicides that will be designed to be specifically targeted agents, which can be applied topically to reduce transmission of HIV during sexual intercourse. CHAARM stands for Combined Highly Active Anti-Retroviral Microbicide. EATG is part of the working group for dissemination and advocacy activities, and has an appointed representative on the CHAARM Steering Committee.

The EATG's role is to help identify target groups for dissemination of CHAARM activities and also to facilitate the organisation of 4 dedicated workshops focusing on CHAARM's scientific ac-

37 In line with objective 3.3.1: EATG is represented at key scientific conferences

tivities and achievements starting from the second year of the project.

On October 12th, 2011, EATG co-organised in collaboration with Minerva (the Communication partner of CHAARM) a satellite session during the EACS conference in Belgrade, Serbia. The pre-opening satellite session "Advances in HIV biomedical prevention research: why involving the Community is key" was organised by EATG, within the framework of CHAARM and was chaired by Jur Strobos, from the Forum for Collaborative HIV Research.

This satellite focused on the ways affected communities can be involved in the design, promotion and implementation of studies of new prevention methods. The importance of this has been illustrated by the premature closure of some prevention trials in the past due to the lack of community support and investment in the trial. Equally, the successful conclusion of a number of other recent prevention trials can be attributed partly to the community involvement being an essential part of the design and the conduct of the trial. In this satellite, key researchers presented how consultation and involvement with the proposed study population is an essential part of trial design, looking at successful models of community involvement and discussing the way community consultation is being incorporated into forthcoming and proposed prevention trials.

The participating speakers were the followings: Charles Kelly - King's College London (KCL), Charles Lacey - Hull York Medical School (HYMS), François Berdougo - TrT-5 (Groupe Interassociatif Traitement & Recherche Thérapeutique), Christiana Noestlinger - Antwerp Institute of Tropical Medicine (ITM HIV/AIDS Center), Gus Cairns - NAM/EATG, David Haerry – EATG.

For further information about the event including the meeting report: http://www.eatg.org/eatg/Scientific-Research/Conferences/EACS-satellite-October-12th-2011-Advances-in-HIV-biomedical-prevention-research-Why-involving-the-Community-is-key

➔ **EUPATI**

EATG became a partner in the European Commission IMI-funded EUPATI project (**European Patients' Academy on Therapeutic Innovation**). EUPATI is a patient-led academy that will provide scientifically reliable, objective, comprehensive information to patients on pharmaceutical R&D. It will increase the capacity of well-informed patients to be effective advocates and advisors, e.g. in pharmaceutical development, with regulatory authorities and in ethics committees. The project started on February 1st 2012.

For further information:
http://www.eatg.org/eatg/Scientific-Research/Projects/The-European-Patients-Academy-on-Therapeutic-Innovation-EUPATI

3.2 ECAB ensures collaboration with national and international partners and networks

EMA – Patient and Consumer Working Party (PCWP)

David Haerry, delegate; Siegfried Schwarze, alternate

Patients and consumers interact with the Agency through the Patients' and Consumers' Working Party (PCWP). This working party consists of a core group of representatives from patients' and consumers' organisations that provide recommendations to the Agency and its human scientific committees on all matters of interest to patients in relation to medicinal products.

This group, which was established in 2006, has enabled the Agency to build upon its existing interaction with patients and consumers, creating a permanent forum for dialogue on the issues that affect them the most.

EMA – Paediatric Committee

Michal Odermarsky, delegate; Milena Stevanovic, alternate

The main responsibility of the Paediatric Committee (PDCO) is to assess the content of Paediatric Investigation Plans and adopt opinions on them including assessment of applications for full or partial waiver and applications for deferrals[38]. Other roles include e.g. assessing data generated in accordance with agreed PIPs; adopting opinions on the quality, safety or efficacy of a medicine for use in the paediatric population, at the request of the Committee for Medicinal Products for Human Use (CHMP) or a medicines regulatory authority in a European Union (EU) Member State. The PDCO can give an opinion if the data have been generated in accordance with an agreed PIP.

In 2011, EATG participated in the following activities:
- acted as rapporteur or peer reviewer for several paediatric investigation plans (PIPs) in area of infectious diseases, cardiovascular diseases, endocrinology –metabolism and diagnostics;
- participated in EMA workshop on heart failure in paediatric population

FORUM FOR COLLABORATIVE HIV RESEARCH

Michal Odermarsky, steering committee member; Stephan Dressler alternate

Founded in 1997, The Forum for Collaborative HIV Research is a public/private partnership at the University of California, Berkeley Washington Campus[39]. The Forum includes representatives from government, industry, patient advocates, health care providers, academia and foundations. The Forum's mission is to enhance and facilitate HIV research and this is accomplished by bringing together all relevant stakeholders to address emerging issues in HIV/AIDS. The goal is to optimise care and treatment of

38 In line with objective 3.2.4: EATG ensures meaningful interaction with EMA

39 In line with objective 3.2.3: ECAB ensures meaningful representation within the HIV research arena

those affected by HIV/AIDS and its scope includes research addressing prevention, treatment strategy, health services utilisation and health policy.

In 2011, EATG participated to the following events organised by the Forum:

- Forum Executive committee meeting, November 30, 2011, Washington DC
- Safety Issues in Pre-exposure Prophylaxis for HIV negative individuals, proposals for management of safety concerns, and pending plans for scale-up

3.3 EATG ensures continued monitoring of trends in HIV/AIDS research and related co-infections

➔ Sitges IV meeting - June 3-5, 2011, Sitges, Spain

On 3-5 June 2011, ECAB hosted the fourth meeting in a series of multi-stakeholder meetings on development of, and access to experimental therapies for Hepatitis C virus (HCV) focusing on "Optimising treatment access and outcomes among difficult-to-treat groups with Hepatitis C and HIV/HCV co-infection"[40].
To this end, the meeting addressed issues faced by people who cannot use interferon, because of contraindications or intolerability, prior null responders to pegylated interferon-based regimens, as well as people who will require approved and experimental DAAs in addition to peg-interferon and ribavirin. Access to these potentially life-saving drugs can be provided through trials and early access programs; different mechanisms are needed to ensure that the medicines will be provided to patients in urgent need. A dialogue between community members, regulators, researchers, clinicians and pharmaceutical industry is needed to facilitate the development of trials and other early access initiatives. The Sitges IV meeting provided a timely opportunity for a multi-stakeholder discussion on these issues.

All information about the event can be found here:
http://www.eatg.org/eatg/Scientific-Research/Conferences/Sitges-IV-Meeting-June-3-5-2011-Sitges-Spain

➔ ECAB ensures representation of delegates at major HIV/AIDS and co-infections scientific conferences

In 2011, ECAB/EATG representatives took an active participation in the following scientific conferences:

- 18th Conference on Retroviruses and Opportunistic Infections CROI, February 27-March 2, Boston
- 6th IAS Conference on HIV Pathogenesis, Treatment and Prevention, July 17-20, Rome
- 13th European AIDS conference (EACS), 12-15 October 2011, Belgrade, Serbia

During the 13th EACS conference EATG presented their "Emergency guidance on ART forced treatment interruptions[41] due to drug unavailability (forced stock-outs) for people living with HIV and their care providers in Europe and Central Asia"[42]. The guidelines were the result of a collaboration between ECAB and the Policy Working Group[43] and were translated and distributed with financial support from our COPE project.

These recommendations came at a critical time, when HIV advocates and UN agencies registered antiretroviral (ARV) treatment interruptions due to stock-outs in several countries within Europe and Central Asia. Due to recurring stock-outs, especially in Central and Eastern Europe, for multiple reasons such as bad planning, bad communication between departments, Ministries not understanding the importance of continuous treatment etc.; the need for the creation of such guidelines was strongly felt. Therefore EATG decided to come up with guid-

40 In line with objective 3.1.2: ECAB maintains and establishes an effective dialogue with stakeholders directly involved in clinical research and/or drug development
41 In line with objective 1.1.5: EATG continuously monitors and raises awareness on ARV treatment interruptions throughout the EU, as well as in the Balkans, Eastern Europe and Central Asia
42 In line with objective 3.3.1: EATG is represented at key scientific conferences
43 In line with objective 7.3.2: ECAB and PWG strengthen their collaboration on cross-cutting issues

ance for the patient community and their organisations. The guidance will help them to be better equipped when problems occur, but also help understanding when interruptions are problematic and when not.

This guidance, issued by the EATG seeks to inform and provide assistance to people living with HIV and their care-takers in case of an ARV treatment interruption. The EATG works on removing and preventing treatment interruptions and we call on national authorities, along with technical support providers and donors, to improve: forecasting and timely and sufficient funding allocations; efficacy of resources and facilitate price negotiations; procurement and supply management of ARV and other medicines.

The guidance is available in English, Russian, Romanian, Serbian and Bulgarian here: http://www.eatg.org/eatg/Publications/Emergency-Guidance-on-ART-forced-treatment-interruptions. More languages will be available soon.

ECAB membership

ECAB had 63 members from EATG within its membership and 37 external members. Via the EATG membership 28 countries are represented including 13 countries from Central and Eastern Europe[44]: Albania; Belarus; Belgium; Bulgaria; Canada; Croatia; Czech Republik; Denmark; Estonia; France; Germany; Greece; Hungary; Italy; Kosovo; Latvia; Lithuania; Macedonia; Netherlands; Portugal; Romania; Russian Federation; Serbia; Spain; Sweden; Switzerland; United Kingdom; United States.

44 In line with objective 4.1.2 : ECAB continues reaching out to the East by diversifying its membership to reach appropriate representation of populations and countries with a high burden of disease

"Our programs are evidence based in order to respond to the needs of those most vulnerable to HIV/AIDS and its consequences."

IV DIVERSIFY FUNDING AND DEVELOP FUNDRAISING STRATEGY

4.1 EATG increases its eligibility criteria by diversifying its funding

The EATG held two fundraising meetings in 2011[45].

Fundraising Meeting June
The focus of this meeting was to discuss the work-flow for core-funding and the longer term strategy.

The participants reached a consensus for the internal procedures for core-funding including the involvement of members and staff as well as timelines and responsibilities. The process of attaining funding is becoming more and more labour intensive due to the development of different application and reporting procedures by funders.

One of the difficulties EATG faces is the lack of knowledge of a large percentage of its funding from one year to the next. Therefore there was an agreement to start developing a two year work plan and operating budget as soon as possible in order to focus the fundraising strategy on securing long term funding for the planned activities well in advance.

Fundraising Meeting November
Here it was important to confirm the role and responsibilities of the EATG Fundraising Task Force, which consists of three staff members and one EATG member and how to better involve other members with fundraising skills. The further discussion included the fundraising plan for 2012 and how to be more pro-active when asking for funding. The group discussed the importance of face-to-face meetings with old, current and new funders.

The group confirmed the importance of good external communication and discussed improvements which included dedicated newsletters after larger events, new EATG logo, Facebook and Twitter etc.

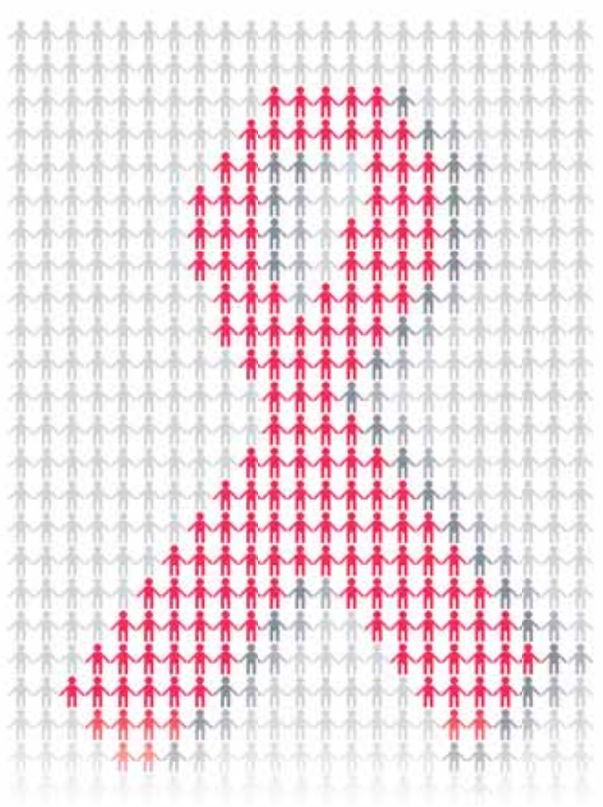
The last part of the meeting covered the evaluation of past activities and how to improve the assessment and necessity of future participation and activities of the organisation. [46]

Social Accounting
In 2011 EATG started a social accounting system - first as a test case. The costs of a non-profit organisation like EATG can be easily measured; but conventional accounting does not capture the value of our non-monetary resources such as our members who work voluntarily. Excluding this undervalues a key and valuable resource which EATG relies on. To start the process of our social accounting we asked as many members as possible to start tracking their EATG time using an especially adapted timesheet for volunteers.

By the end of 2011 the value of volunteer time was 389.363 EUR.

Stakeholders meeting
Approximately 30 partners and donors joined our stakeholders meeting on June 10th 2011[47]. The meeting was organized to share the results of our work and discuss ideas and projects for the coming years with our stakeholders. Koen Block, EATG Executive Director, also provided a short introduction to the recently published annual report of 2010, to the planned long term strategy 2012 – 2015 and some of the events planned for 2011 (see also http://www.eatg.org/eatg/Publications/Workplans-and-activity-reports/EATG-Long-Term-Strategy-2012-2015).

45 In line with objective 5.1.1: EATG continues the work done within the fundraising Task Force
46 In line with objective 5.1.2: EATG maintains its funding levels and continues to diversify its funding sources with 20% non-pharma funding in 2011 and 30% in 2012
47 In line with objective 5.1.4: EATG improves communication and interaction with stakeholders



48 In line with objective 5.1.3: EATG continues the implementation of a transparent funding and fundraising strategy

Transparency

The EATG has been working hard on achieving the highest possible levels of transparency in its work[48]. We always scored high in transparency barometers from the 'Fondation Prometheus' that evaluate how transparent the work of NGOs is, based on the information they provide on the internet (publicly accessible information).
You can download the latest barometer at:
http://www.fondation-prometheus.org/main.php?act=page&s=barometre_ong

EATG is a signatory and active contributor of the constantly evolving "Renewing Our Voice - Code of Good Practice for NGOs Responding to HIV/AIDS".

This Code sets out a number of Guiding Principles which apply a **human rights approach** to the range of HIV/AIDS-specific health, development and humanitarian work undertaken by NGOs responding to HIV/AIDS. The principles provide a common framework applicable to all NGOs engaged in responding to HIV/AIDS. They are embodied within good practice principles, which guide both how we work as NGOs and what we do. It also includes key resources such as tool kits and manuals that can assist in putting the principles into practice, and also information about the process of 'signing on' to the Code and about implementation of the Code.

The Code of Good Practice can be found at
http://www.eatg.org/About-us/Transparency

EATG Income 2011

	AMOUNT IN EURO	PERCENTAGE OF TOTAL INCOME
Donations		
Boehringer-Ingelheim GmbH	71,000	6.49%
GILEAD	199,295	18.21%
MSD	151,820	13.87%
BMS	45,000	4.11%
ROCHE	64,338	5.88%
ABBOTT	24,000	2.19%
TIBOTEC	107,000	9.78%
ViiV	160,000	14.62%
GSK	7,000	0.64%
GLOBAL ALLIANCE	3,474	0.32%
Other	8,465	0.77%
Projects		
HIV in Europe	12,632	1.15%
Intergroup (funded by Gilead)	26,439	2.42%
COPE (funded by BMS)	19,441	1.78%
EUROPRISE (EC)	28,125	2.57%
Correlation Network II (EC)	21,512	1.97%
Training Grant (funded by BMS)	30,015	2.74%
Training Grant (funded by Sidaction)	24,497	2.24%
AIDS & Mobility (EC)	23,045	2.11%
NEAT (EC)	49,233	4.50%
Advance payments	-3,806	-0.35%
Total	**1,072,525**	**98.01%**
Membership fees	**2,725**	**0.25%**
Interest	**2,174**	**0.20%**
Recoverable costs		
European Commission	3,685	0.34%
Correlation Seminar	3,365	0.31%
EPHA	2,083	0.19%
Other reimbursements	6,716	0.61%
Total	**15,849**	**1.45%**
Other	**1,029**	**0.09%**
Total income 2011	**1,094,302**	**100.00%**

EATG Expenditure 2011

	EXPENDITURE IN EURO
Governance & Administration	
Secretariat	109,306
General Assembly	51,640
Board of Directors	60,930
Development and Membership Advisory Group	7,146
Internal Auditors	5,561
Fundraising	19,739
Strategy Development	20,406
External Auditors	11,961
Handbook Review	2,627
TOTAL	**289,316**
Policy & Advocacy	
Policy Working Group meetings & external representation	123,952
InterGroup	24,358
Correlation Network II Project	58,041
HIV in Europe Project	25,088
TOTAL	**231,438**
Research & Development	
ECAB meetings, protocol reviews & conference representation	269,102
EUROPRISE Project	30,066
NEAT Project	47,129
CHAARM Project	10,641
TOTAL	**356,938**
Capacity Building	
EATG Trainings	110,702
COPE	19,441
AIDS & Mobility Project	26,055
Other conference support	4,004
TOTAL	**160,202**
Communication	
Website content management, publications & IT support	27,804
TOTAL	**27,804**
Grand Total	**1,065,699**

"We address the causes of vulnerability to HIV infection and the impact of HIV/AIDS."

V SUSTAIN AND DEVELOP EATG'S VISIBILITY

Newsletters

Our newsletters are an important tool to inform stakeholders about our work and activities. This is also an opportunity for our members to share information about their work in their home organisations and the situation at country level. In 2011 we produced and distributed two external newsletters and we plan to increase the number in the coming years[49].

External News April 2011:

- EATG supporting scientific research and development
- Que será en 2011? Our plans for EATG's policy and advocacy work
- Game is Over! Responsibilities for health of prisoners must move from the Ministries of Justice to the Ministries of Health
- EATG building capacity

External News November 2011:

- Breaking the barriers, bridging the gaps: health inequalities, the HIV response and political leadership in the European Union
- Correlation Network II: HIV/AIDS Policy Recommendations
- EATG salutes and supports the launch of the Network of Low Prevalence Countries in central and South Eastern Europe
- European Community Advisory Board (ECAB)
- Emergency Guidance on ART forced treatment interruptions
- Providing information for people living with HIV: a short overview on EATG activities until 2008
- Guarding against complacency: community involvement is key to providing a successful response to the HIV epidemic

Our electronic internal newsletters are sent to members only. We use the Events Brief to inform members about internal meetings and share reports from meeting members attended. We have sent three internal newsletters in 2011 instead of six as initially foreseen.

Internal News February 2011 – we reported on:

- Civil Society Meeting, October 25-27, Luxembourg
- ILGA Europe Conference, October 28-31, The Hague, Netherlands
- 9th Nordic Patient Meeting on HIV: "Positive Living – current issues and European networking", November 3-4, Amsterdam, Netherlands
- Seminar 2 of the HPYP project, November 4-5, Lisbon, Portugal
- Conference: Can we afford the current model of medical innovation?, November 18, Brussels, Belgium
- Correlation seminar on Outreach and peer support, November 18-20, Prague, Czech Republic
- HIV Academy meeting, November 19-20, Sofia, Bulgaria
- EPPOSI Board and Annual General Assembly Joint Meeting, November 24, Brussels, Belgium
- The Future of MSM Prevention in Europe – FEMP 2011, January 13-14, Stockholm, Sweden
- EATG Community Meeting on R&D priorities in Pre-Exposure Prophylaxis (PrEP) for HIV
- Master Toolkit Advisory Board and Master Toolkit, aids&mobility
- Policy Working Meeting, February 19-21, Riga, Latvia

Internal News April 2011 – we reported on:

- EUROCOORD Kick-off Meeting, January 12, London
- EACS 2011 Scientific and Programme Committee Meeting, January 18, Paris
- IAS/EATG Meeting, February 2, Geneva
- Study visit on HIV Prevention, P2P European Commission, February 22-25, Brussels
- 18 Conference on Retroviruses and Opportunistic Infections CROI, February 27-March 2, Boston

49 In line with objective 6.1.1: EATG establishes internal procedures for timely production and distribution of external announcement

- Europrise Networking Meeting, March 7, New York
- CHAARM Steering Committee, March 14-16, Camogli
- European Commission's Civil Society Forum on Drugs, April 12-13, Brussels
- Policy Working Meeting, February 19-21, Riga, Latvia
- Breaking the barriers, bridging the gaps: health-inequalities, the HIV/AIDS response and Political Leadership in the European Union, HIV/AIDS Correlation Policy Dialogue, 29-30 June, Brussels

Internal News July 2011 – we reported on:

- Cobasys Mid-term meeting, April 27-29, Windhoek, Namibia
- GNP+ Annual Board and Regional Coordinators Meeting , May 15-18, Amsterdam, The Netherlands
- NEAT General Assembly, May 16-17, Rome, Italy
- The Global Commission on HIV and the law - Report from the regional consultation on Eastern Europe and Central Asia, May 18-19, Chisinau, Moldova
- AIDS 2011 "HIV in the European Region – Unity and diversity", 25-27 May, Tallinn, Estonia
- Medical Innovation Prizes instead of Monopolies, May 31, Brussels, Belgium
- Second stakeholder forum on the implementation of the new pharmacovigilance legislation, June 17, London, United Kingdom
- UNAIDS Programme Coordinating Board (PCB), June 21-23, Geneva, Switzerland
- EATG Long-Term Strategy 2012-2015 – Update
- Training 2011

Website and Digest news

EATG continues offering the service of daily Global HIV News for everyone interested in the latest development around HIV/AIDS: prevention, treatment, access to treatment, EMA & FDA, Hepatitis, Tuberculosis & Malaria, Basic Science, EU Policy, World Policy, Pharma Industry, HIV and STIs, MSM, Epidemiology. To subscribe click here - http://www.eatg.org/eatg/Newsletter/Daily-Digest.[50]

Development new visual identity (launch September 2012)

We have worked with a group of designers and EATG members to develop a new image for EATG[51]. Visual guides were produced and the new logo and image will be launched in 2012. From September 2012, marking our 20 years anniversary, EATG will have a totally new look.

In 2011 we sent out several press releases, open letters and public statements regarding scientific and policy issues[52].

These letters and press releases reacting to often acute problems relating to the provision of access to state of the art HIV treatment and care and related issues:

January:

- Letter to Mr Bundulis from the Latvian government asking to improve access to hepatitis C treatment - asking the Latvian government to consider the possibility to cover 75% of price of hepatitis C treatment after receiving information that access to hepatitis C treatment in Latvia has been impeded since the beginning of 2011
- Petition for evidence-based drug policies in Hungary

March:

- Letter to Dr Broun from UNAIDS regarding civil society engagement to activities related to UNAIDS strategic plan - discuss and define how UNAIDS will involve civil society in regional level and country level activities related to the strategy.

May:

- Putting health and human rights first:

50 In line with objective 6.1.3: Communicate up-to-date information about EATG and its activities via www.eatg.org and other channels

51 In line with objective 6.1.4: Improve the visibility of EATG's work by developing an EATG "trust mark"

52 In line with objective 6.1.2: EATG develops relation with national, European and international media

EU HIV/AIDS Civil Society Forum statement on the future drug policies in the EU and beyond

July:

- Letter to WHO Regional Director for Europe, Zsuzsanna Jakab – to congratulate her with the good HIV and TB plans that are to be approved at the Regional Committee meeting in September. The letter was initiated along with other regional networks, ITPCru, ECUO, EHRN, as well as HIV Europe and AIDS Action Europe.
- Press release - UNITAID Patent Pool - 6th IAS Conference on HIV Pathogenesis, Treatment and Prevention - AIDES, the European AIDS Treatment Group, the international community of women living with HIV and AIDS, the Forum della Società civile italiana sull' HIV/AIDS & Coalition PLUS call on Merck, J&J and Abbott to join the Patent Pool thereby allowing production of their antiretroviral in the South. If not they will be accomplices to HIV transmission and the death of millions of HIV positive people.
- Press Release - U.S. and E.U. break UN AIDS Summit Commitments on Access to Treatment - AIDS Groups outraged as EU and US continue "immoral blackmail" on generic AIDS medicines through Free Trade Agreement Negotiations.

August:

- Open letter to the Ambassador of South Korea to Belgium

EATG decided to send a letter to express their shock and outrage at the Korean police and security guards' actions—violently arresting peaceful demonstrators at the International Congress on AIDS in Asia and the Pacific (ICAAP) in Busan. EATG joined civil society groups from throughout the world in demanding an unconditional apology from the South Korean Government, the South Korean Police and the conference security guards.

- Position: Treatment activists, people living with hepatitis C, people who inject drugs and people living with HIV openly question the silence maintained by the World Health Organisation (WHO) - Preventable hepatitis C related deaths continue to occur as the WHO maintains silence on the hepatitis C epidemic.

September:

- Open letter to Michel Kazatchkine, Executive Director of the Global Fund to Fight AIDS, Tuberculosis and Malaria - Statement on the Report of the 'High-Level Independent Review Panel on Fiduciary Controls and Oversight Mechanism of the Global Fund to Fight AIDS Tuberculosis and Malaria'

October:

- Press release - Advances in HIV biomedical prevention research: why involving the Community is key - On Wednesday 12 October from 9.30 to 11.00 am, during the EACS conference in Belgrade, Serbia, the European AIDS Treatment Group (EATG) is organising the pre-opening satellite session "Advances in HIV biomedical prevention research: why involving the Community is key".
- Press release - EATG launches Emergency Guidance on ART forced treatment interruptions due to drug unavailability - The European AIDS Treatment Group (EATG) launches the "Emergency guidance on ART forced treatment interruptions due to drug unavailability (forced stock-outs) for people living with HIV and their care providers in Europe and Central Asia"
- Press Release - Activists meet in Belgrade to advance the newly launched Network of Low HIV Prevalence Countries in Central and South East Europe (NeLP) - Dangerous shortages of treatments and diagnostics are prime issue in the regions today.

November:

- **Joint statement** - We need the Patent Pool to work - a statement by Treatment Action Campaign, Treatment Action Group, HIV i-Base, European AIDS Treatment Group and SECTION27.

December:

- **HIV in Europe welcomes the European Parliament resolution on the EU response to HIV/AIDS in the EU and neighbouring countries and the strong commitment to HIV expressed by the European Commission** - "The HIV in Europe initiative welcomes the European Parliament resolution on the EU response to the HIV/AIDS epidemic in Europe and neighbouring countries adopted on World AIDS day.

Other important communication sent throughout the year:

- Letter to European Commissioner Karel de Gucht regarding FTA negotiations between India and the EU
  An EATG letter to European Commissioner Karel de Gucht raising concerns relating to the availability and affordability of generic medicines to be discussed in the EU-India Free Trade Agreement negotiations
- Putting health and human rights first: EU HIV/AIDS Civil Society Forum statement on the future drug policies in the EU and beyond
  The HIV community across Europe call on the European Commission, European Parliament and EU member states to express political leadership in combating HIV/AIDS in the EU and neighbouring countries
- Petition for evidence-based drug policies in Hungary
  EATG has signed the petition of NGOs, service providers and activists urging the Hungarian government to return to the principles of a balanced and evidence-based drug policy.

"EATG has been at the forefront of the development of the civil society response to the HIV/AIDS epidemic in Europe."

VI DEVELOP AND MAINTAIN EFFECTIVE INTERNAL SYSTEMS

6.1 EATG ensures adequate reporting & communication to its members

The EATG extranet is continuously updated for use by its members and reports from events are sent via our internal newsletters (see page 29).

6.2 EATG continuously updates and evaluates WG membership and membership processes

The Development and Membership Advisory Group (DMAG)
DMAG chair: Jens Wilhemsborg

DMAG is the internal group dealing with membership issues and internal working mechanisms. During the General Assembly in Berlin (2011) the group announced its change of name from Development Membership Working Group (DMWG) to Development Membership Advisory Group (DMAG). The group did have 5 members within DMAG in 2011. 9 applications were reviewed by the group and 8 new member applications were approved.

The EATG Membership
The EATG membership consists of individuals who are mainly active in their country of residence, in local community-based organisations, research centres in universities, governmental agencies and public services, scientifically trained health professionals from various fields and individuals involved in advocacy in international networks, institutions and organisations.

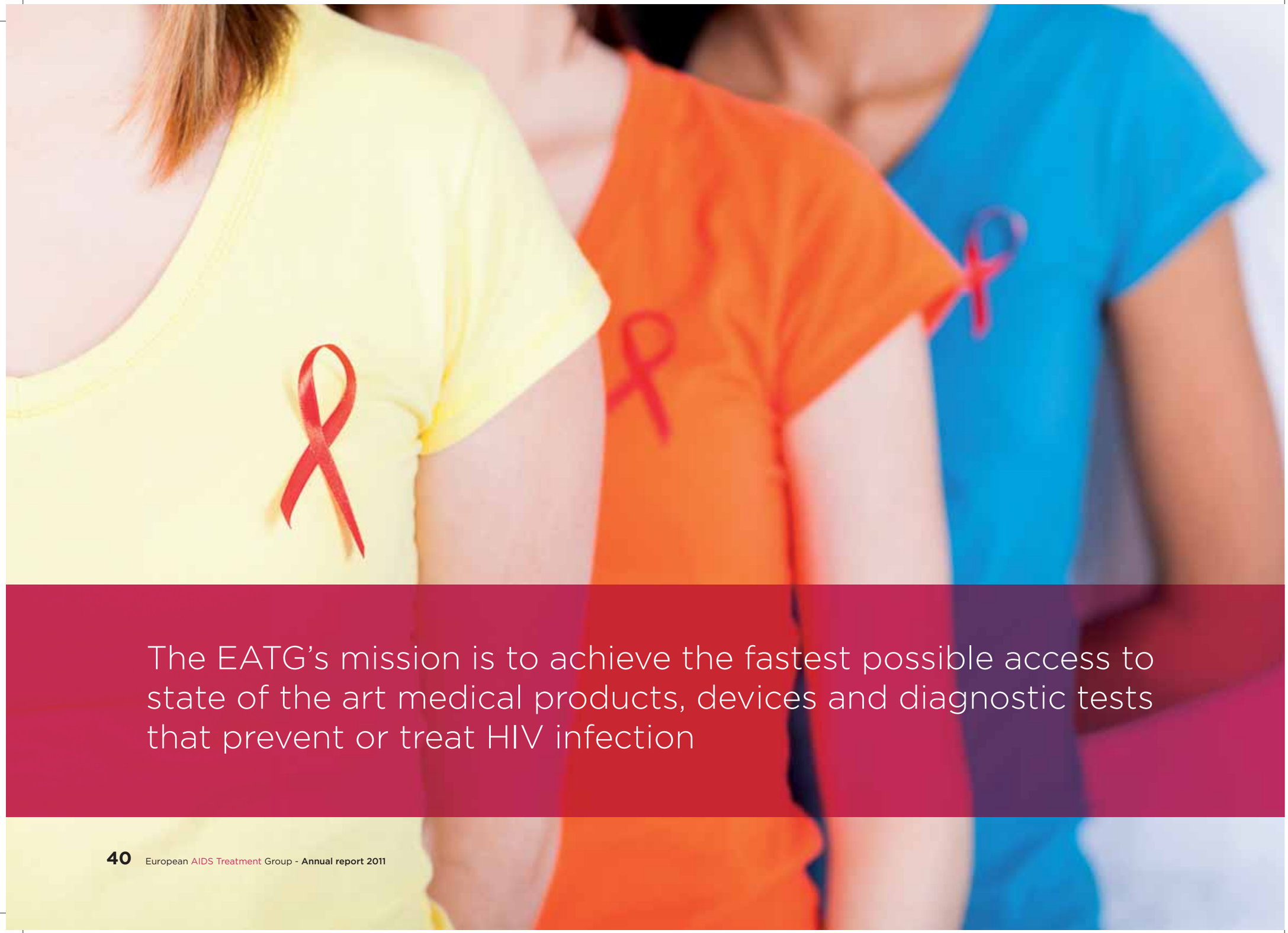
People who want to apply for membership can send their application via our website. The application form was updated, as well as the Declaration of Interest document which allows EATG to see if there are potential conflicts of interest within the membership. The EATG welcomes members from the WHO Europe region. The Development and Membership Advisory Group (DMAG) is in charge of the evaluation of new members' applications[53]. Candidates must be fluent in English and be involved in activities related to the EATG mission statement in their country of residence. Preference is given to people living with HIV/AIDS.

The membership handbook was reviewed and changes were presented at the General Assembly[54]. Some further work will be done during 2012. In January 2011 we had 99 members (64 ordinary members; 35 supporting members. Ordinary members have voting rights, supporting members not. After 1 year supporting members can become ordinary members.). By December 2011 our membership increased to 108 members (69 ordinary; 39 supporting). Starting with 28 women in January and 71 men, we ended the year with 28 women and 80 men. At the end of 2011 EATG had supporting and ordinary members in 39 countries including[55] 1 member from Canada and 4 members from the US. Our members were active in the following countries in Europe and Central Asia: Albania, Armenia, Belarus, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Kosovo, Kyrgyzstan, Latvia, Lithuania, Macedonia, Netherlands, Portugal, Romania, Russian Federation, Serbia, Slovenia, Spain, Sweden, Switzerland, Tajikistan, Turkey, Ukraine, United Kingdom and Uzbekistan.

The increase in membership was also reflected in the number of countries represented by our members. Compared to 2010, 9 more countries were represented within our membership, which led to a more empowered representation from the different regions of Europe within the EATG.

The HIV status of around 80% of our members is known. At the end of 2011 around 58,3 % of all members (both supporting and ordinary) were people living with HIV.

53 In line with objective 7.2.2: Systems to welcome and integrate new members are developed
54 In line with objective 7.2.3: The EATG handbook is reviewed
55 In line with objective 7.2.1: The EATG membership and membership systems are monitored, evaluated, updated



The EATG's mission is to achieve the fastest possible access to state of the art medical products, devices and diagnostic tests that prevent or treat HIV infection

VII ABOUT EATG

The EATG, founded in 1992, is a NGO that defends the interests of people living with HIV/AIDS by focusing on treatment activism and treatment advocacy. We try to influence changes in legislation that will contribute to the increased access to HIV treatment and care, and monitor the process of development, testing and approving of HIV treatments, in respect to the needs and rights of the people living with HIV.

In responding to HIV, the EATG also considers diseases frequently seen as co-infection in people with HIV, such as hepatitis and tuberculosis, as well as other health issues that increase the risk of HIV.

As a European patient-led advocacy organisation, the EATG has been at the forefront of the development of the civil society response to the HIV/AIDS epidemic in Europe for many years. It represents and defends the treatment-related interests of people living with HIV and AIDS.

Mission

The EATG's mission is to achieve the fastest possible access to state of the art medical products, devices and diagnostic tests that prevent or treat HIV infection or improve the quality of life of people living with HIV, or who are at risk of HIV infection.

Guiding Principles

- We advocate for the meaningful involvement of PLHA and affected communities in all aspects of the HIV/AIDS response.
- We protect and promote human rights in our work.
- We apply public health principles within our work.
- We address the causes of vulnerability to HIV infection and the impact of HIV/AIDS.
- Our programs are evidence based in order to respond to the needs of those most vulnerable to HIV/AIDS and its consequences.

EATG Global Aims

- To enable people with HIV or at risk of HIV infection and their supporters to significantly influence the development, testing and approving of HIV treatments. In this context, HIV treatment means medical devices, products and diagnostic tests that prevent or treat HIV infection and include continuous improvement in the quality of life of people affected.
- To advocate for the best practices of care and treatment.
- To advocate for rapidly available existing and new HIV treatment.
- To promote the access of the latest available information about treatment legislation for patients, health care providers as well as policy makers.
- To influence changes in legislation and patent law in order to support the lowest achievable cost for HIV treatment, including the support for generic medicine.
- To monitor the changes in Health care systems and policies to ensure the rights and the quality of services influence positively the quality of life of people living with HIV/AIDS.

EATG and its networks and partners

To perform its activities and to reach its goals, the EATG works closely together with many different actors on the field. This collaboration creates a broader support to our activities, but also a higher quality of the actions taken. This (non-exhaustive) list shows some of our core networks and partners in the field:

EU Institutions and Executive Agencies

DG Sanco – Health and Consumer Protection; DG Enterprise and Industry; DG Research; DG Trade; European Parliament; European Medicines Agency (EMA); European Monitoring Centre for Drugs and Drug Addiction (EMCDDA); European Centre for Disease Control (ECDC)

Other EU Platforms
EU Health Policy Forum; HIV/AIDS Civil Society Forum (CSF); Pharmaceutical Forum

United Nations programs and organisations
UNAIDS, the Joint United Nations Programme on HIV/AIDS; World Health Organisation (WHO), the directing and coordinating authority for health within the United Nations

International Organisations
International Organisation for Migration (IOM); International Harm Reduction Association (IHRA); International AIDS Society (IAS); International Planned Parenthood Federation (IPPF)

HIV/AIDS Organisations and Networks
AIDS Action Europe; AIDS Treatment Activists Coalition (ATAC); International Treatment Preparedness Coalition (ITPC); Global Network of People Living with HIV/AIDS (GNP+); International Community of Women Living with HIV/AIDS (ICW); Eastern European & Central Asian Union of PLWH Organisations (ECUO); Global Campaign for Microbicides (GCM); International AIDS Vaccine Initiative (IAVI); AIDS Vaccine Advocacy Coalition (AVAC); HIV in Europe; NAM; Terrence Higgins Trust (THT)

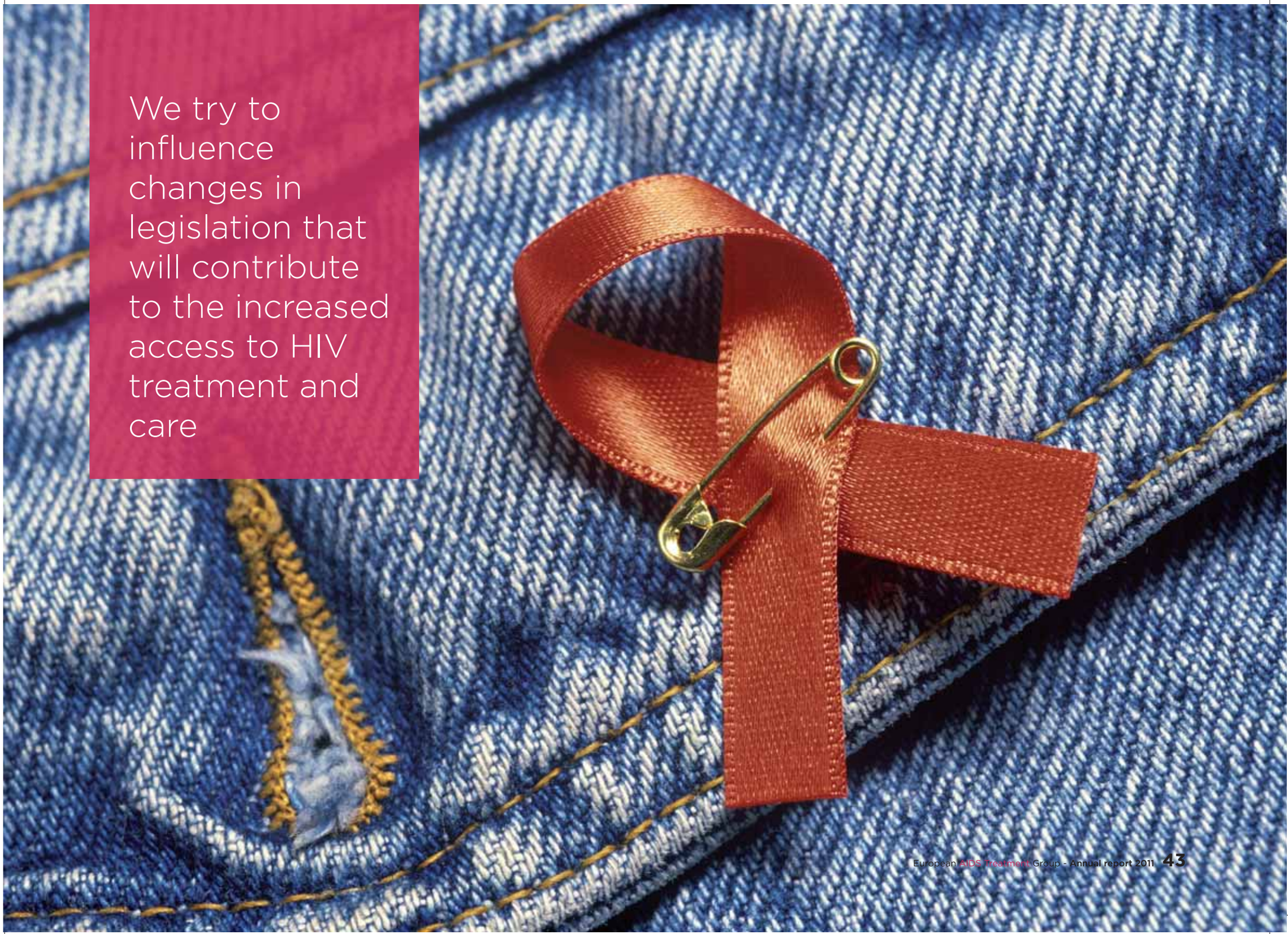
Public Health Networks
European Public Health Alliance (EPHA); Concord; EU Civil Society Contact Group; International Harm Reduction Development Program (IHRD); Eurasian Harm Reduction Network (EHRN); Health Action international (HAI); Médecins Sans Frontières (MSF), European Forum for Good Clinical Practice (EFGCP)

EATG involvement via projects
AIDS and Mobility Europe; AIDS Action Integration; European HIV Resistance Network; HIV/STI Prevention & Health Promotion among Migrant Sex Workers (TAMPEP); Health GAP (Global Access Project); European AIDS Treatment Network (NEAT); Europrise

Other European organisations
European Patients' Forum (EPF); International Alliance of Patient Organisations (IAPO); European Forum for Good Clinical Practice (EFGCP); European Federation of Pharmaceutical Industries and Associations (EFPIA); European Coalition of Positive People (ECPP); European AIDS Clinical Society (EACS); European Platform for Patients Organisations, Science and Industry (EPPOSI)

Other organisations and networks
Platform for International Cooperation on Undocumented Migrants (PICUM); Open Society Institute (OSI); Human Rights Watch (HRW); Correlation European Network Social Inclusion and Health; The Global Fund to fight AIDS, Tuberculosis and Malaria (GFTAM); Global Health Council; Association Internationale de la Mutualité (AIM); European Consumer's Organisation (BEUC); Comité Permanent des Médecins Européens (CPME); the European Network on Drugs and Infections Prevention in Prison (ENDIPP)

We try to influence changes in legislation that will contribute to the increased access to HIV treatment and care



VIII EATG GOVERNANCE

EATG strengthens its governance systems

EATG has been working on two different strategies during the year 2011: a 2012 work plan and a Long Term Strategy. In order to have involvement of our membership in these procedures the strategy development happened in collaboration between staff, chairs, BOD, some members .

EATG's new **Long Term Strategy**[57] is covering 2012 – 2015. Our previous strategy covered the period of 2007 – 2010. The new Long Term Strategy was finalised and shared with members and stakeholders early 2012.

We also started developing a **2012 work plan**[58]. The work plan was approved by the BOD in January 2012.

A **2010 annual report** was created which was shared with our members and external stakeholders in June 2011[59].
EATG has representatives in many steering committees, advisory boards, scientific committees etc. We performed a mapping of all positions we have[60].

56 In line with objective 7.3.1: WG governance systems are reviewed and strengthened
57 In line with objective 7.3.4: EATG develops a new 2012 - 2015 Long term Strategic Plan
58 In line with objective 7.3.3: A 2012 workplan is developed
59 In line with objective 7.3.5: EATG develops a 2010 year report
60 In line with objective 7.3.6: EATG starts a reviewing (assessment) and strengthening process of EATG's representation in bodies and reporting mechanisms

The Board of Directors

The EATG General Assembly elects the Board of Directors (2 year term). The Board of Directors is given its mandate by the GA and is bound by its decisions.

EATG BOD from January 1 until September 11, 2011:
Anna Żakowicz, Lithuania - Chair
David Haerry, Switzerland - Secretary (resigned as of May 1st, 2011)
Stefan Stojanovik, Macedonia - Treasurer
Luis Mendão, Portugal - Vice-chair
Alain Volny-Anne, France - Director
Ferenc Bagyinszky, Hungary – Director (became secretary starting from May 1st, 2011)

EATG BOD from September 11 until December 31, 2011:
Ferenc Bagyinszky, Hungary - Chair
Stefan Stojanovik, Macedonia - Treasurer
Brian West, UK - Secretary

The EATG General Assembly

The General Assembly is the highest decision-making body of the EATG. It is held once every year to discuss EATG's strategy, priorities and activities. The General Assembly consists of EATG members (both supporting and ordinary members). All ordinary members have voting right.

The GA 2011 took place in Berlin (September 9-11, 2011).


AIDS
HIV
infections
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patients
people
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cancers
immune
virus
HIV-infected
cause
common
million
symptoms
individuals
opportunistic
many
known
lymphoma
deaths
countries
caused
Kaposi's
TB
Pneumocystis
Africa
blood
illness
Signs
early
lymphomas
primary
sarcoma
cells
cervical
called
Patients
cases
used
HIV/AIDS
Health
advent
transmitted
chronic
conditions
present
seen
increased
causes
presents
CD4
cytomegalovirus
one
large
usually
problem
infected
may
develop
Neurological
cancer
tumors
hepatocellular
fluid
side
Mycobacterium
treat
human
due
head
worldwide
PCP
first
primarily
lower
death
case
estimated
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Gastrointestinal
rare
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including
health
transmission
considered
world
new
psychiatric
normally
especially
nerve
HPV
EBV
complex
children
now
pandemic
brain
less
among
Organization
KSHV
identified
developing
associated
CMV
gastrointestinal
several
drugs
nervous
years
year
affect
papillomavirus
patient
particular
immunocompetent
advanced
incidence
viruses
diarrhea
area
tract
lungs
effect
treatment
per
fevers
cell
Sexual
bacterial
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Western
diagnosis
Prevention
therapy
membrane
causing
course
syndrome
pneumonia
viral
Tuberculosis
Tumors
particularly

IX LEGAL STATUS

Registered charity

In Germany where tax deductibility applies and in Belgium as an International non-profit association
The European AIDS Treatment Group (EATG) is a voluntary membership-based patient organisation. The EATG was legally registered on 23/02/1992 as a non-profit organisation at the Amtsgericht Düsseldorf office (VR 8542) and at the tax office Düsseldorf-Mitte under Charity No. 133/5906/0955.

EATG official address in Germany: Mettmanner Str. 24-26, 40233 Düsseldorf, Germany

The EATG is also registered in Belgium as an 'Association Internationale Sans But Lucrative (AISBL)'.

EATG official address in Belgium: Place Raymond Blyckaerts 13, B-1050 Brussels, Belgium

Becoming a donor

Bank Name: ING Bank
Bank Address: 1 Rue du Trône B-1000 Brussels Belgium
Account Name: European AIDS Treatment Group (EATG)
Bank Account n°. 310-1802319-48
IBAN Number BE 11 3101 8023 1948
SWIFT Number BB RU BE BB

EATG has the ECOSOC (Economic and Social Council) consultative status.

EATG is registered within the EC transparency register.

EATG permanent representations

AIDS Action Europe, member Steering Committee • AIDS & Mobility, member Steering Committee, work package leader • AIDSMAP.com • CHAARM, Combined Highly Active Anti-Retroviral Microbicides, member Steering Committee • CHAIN, Collaborative HIV and Anti-HIV Drug Resistance Network, member Advisory Board • Correlation Network II, member Steering Committee, work package leader • Collaboration of Observational HIV Epidemiological Research in Europe • COHERE, Collaboration of Observational HIV Epidemiological Research Europe, member Steering Committee • DG Sanco, Civil Society Forum on HIV/AIDS, Co-Chair, delegates and member of coordination team • DG Sanco, Think Tank on HIV/AIDS, Co-Chair • Drug Interactions Website (www.hiv-druginteractions.org), member Advisory Board • EACS, European AIDS Clinical Society, member Steering Committee • EASL, member of Board of Directors • ECDC: Dublin Declaration Advisory Board, member Advisory Board • ECOSOC (UN Economic and Social Council), consultative status • ECRIN, European Clinical Research Infrastructures Network, member Advisory Board • EMA Patient & Consumer Working Party, Co-Chair • ENCePP, member Steering Committee • EPHA, European Public Health Alliance, member organisation, representative Executive Committee • EPPOSI, European Platform for Patients' Organisations, Science and Industry, member Board of Directors • Euconet, member Steering Committee • EUROPAT • EFGCP, European Forum for Good Clinical Practice • European Harm Reduction Network • European Meeting on HIV & Hepatitis - Treatment Strategies and Antiviral Drug Resistance, Organizing Committee • Europrise, European Vaccines and Microbicides Initiative, member of Steering Committee • Forum for Collaborative HIV Research • Glasgow HIV 2012, International Congress on Drug Therapy in HI Infection, member Steering Committee • GNP+, member Board of Directors • HAART, member oversight Committee • HIV in Europe, member Steering Committee, advocacy Secretariat • HIV/TB representative at World Health Organization • HPYP, Health Promotion for Young Prisoners, member Steering Committee • IAS, International AIDS Society, member Scientific Committee • International Workshop on HIV Pediatrics, member Steering Committee • MSM Global Forum, member Steering Committee • NEAT, European AIDS Treatment Network, member Steering Committee • OPICARE, member Steering Committee • Patient Partner Project, Identifying the needs of patients partnering in clinical research, conference representative • Pedriatic European network for Treatment of AIDS (PENTA) • PROTECT External Advisory Board • STOP TB Partnership • Swedish Conference on HIV/STI prevention for MSM, member Steering Committee • WECAREHIV, Board of Trustees • WHO Europe, Memorandum of Understanding • UNAIDS, Program Coordinating Board

EATG funders

Abbott • Boehringer-Ingelheim • Bristol-Myers Squibb • European Commission • Gilead • GlaxoSmithKline • The Global Alliance • HIV in Europe • Janssen • Levi Strauss Foundation • MSD • Roche • Sidaction • ViiV Healthcare

EATG
EUROPEAN AIDS TREATMENT GROUP