2013
towards global access

Annual Report
(January – December 2013)

EATG
European
AIDS Treatment
Group

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Facts & figures in 2013

43 representations in other organisations and committees

33 countries represented in policy

33 countries represented within ECAB

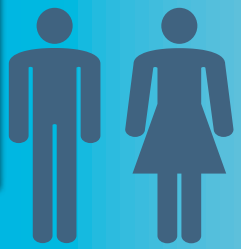
3 ECAB meetings on HIV (February; April; September)

6 speeches at political meetings

1 event in front of European Parliament for the testing week

Over 250 supporters (individuals and organisation) subscribing the **Community Consensus Statement** on Treatment as Prevention

A systematic review of the European Community Advisory Board model



470 organisations supporting the **European HIV testing week**

3 thematic **ECAB meetings** (TB in May; HCV in June and December)

3 presentations within the **European Parliament**

1 multi-stakeholders meeting on HCV compassionate use

2 HIV **Civil Society Forum** and **2** EU **HIV Think Tank** meetings

19 activities on human rights

17 policy activities on access

A symposium on the development of prevention strategies based on Combined Highly Active Anti-Retroviral Microbicides at the EACS conference

A **catalogue** and a **report** on successful public private partnerships (PPPs) between **patients' organisations, industry** and **academia** in collaboration with EUPATI members

Support for the **translation of 4 publications** through the **COPE project** in Armenia, Portugal, Serbia and Slovenia

9 protocols reviewed

5 follow-up projects completed, covering a total of **176 direct beneficiaries** and about **2000 indirect beneficiaries**

3 trainings delivered in 3 countries (in Russia, in Ukraine and in Belgium) for 67 trainees **Countries** covered: Russia, Ukraine, Belarus, Armenia, Kazakhstan, Uzbekistan, Kyrgyzstan, Romania, Tajikistan, Spain, UK, Albania, Macedonia, Greece, and Germany

Average of **392 website visits** per day

Average of **5972 unique visitors** on **our website** month

About us

The European AIDS Treatment Group (EATG) is a European network of nationally-based volunteer activists. Our members are representatives of different communities affected by HIV/AIDS in Europe.

In responding to HIV, EATG considers diseases frequently seen as co-infection in people with HIV, as well as other health issues that increase the risk of HIV of prime importance. In the past few years EATG has increased its activities on co-infections such as **hepatitis C,** hepatitis B and tuberculosis.

Our primary geographic focus is member states served by the World Health Organisation (WHO) Regional Office for Europe. However, European AIDS Treatment group considers all potential opportunities for collaboration and support of similar efforts in other parts of the world. Access to the best available treatments is a major goal for the EATG. This includes:

- Access to all people who could benefit from the treatment, including so-called 'sub-populations' like drug-users, women, children, migrants, people with hepatitis or tuberculosis co-infection, with haemophilia and other.
- Access for patients in all stages of HIV infection (including first-line, salvage)
- Access to treatment in all European countries (according to WHO definition of Euro region)

The **European Community Advisory Board** (ECAB) meets several times a year with the pharmaceutical industry and researchers. 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.

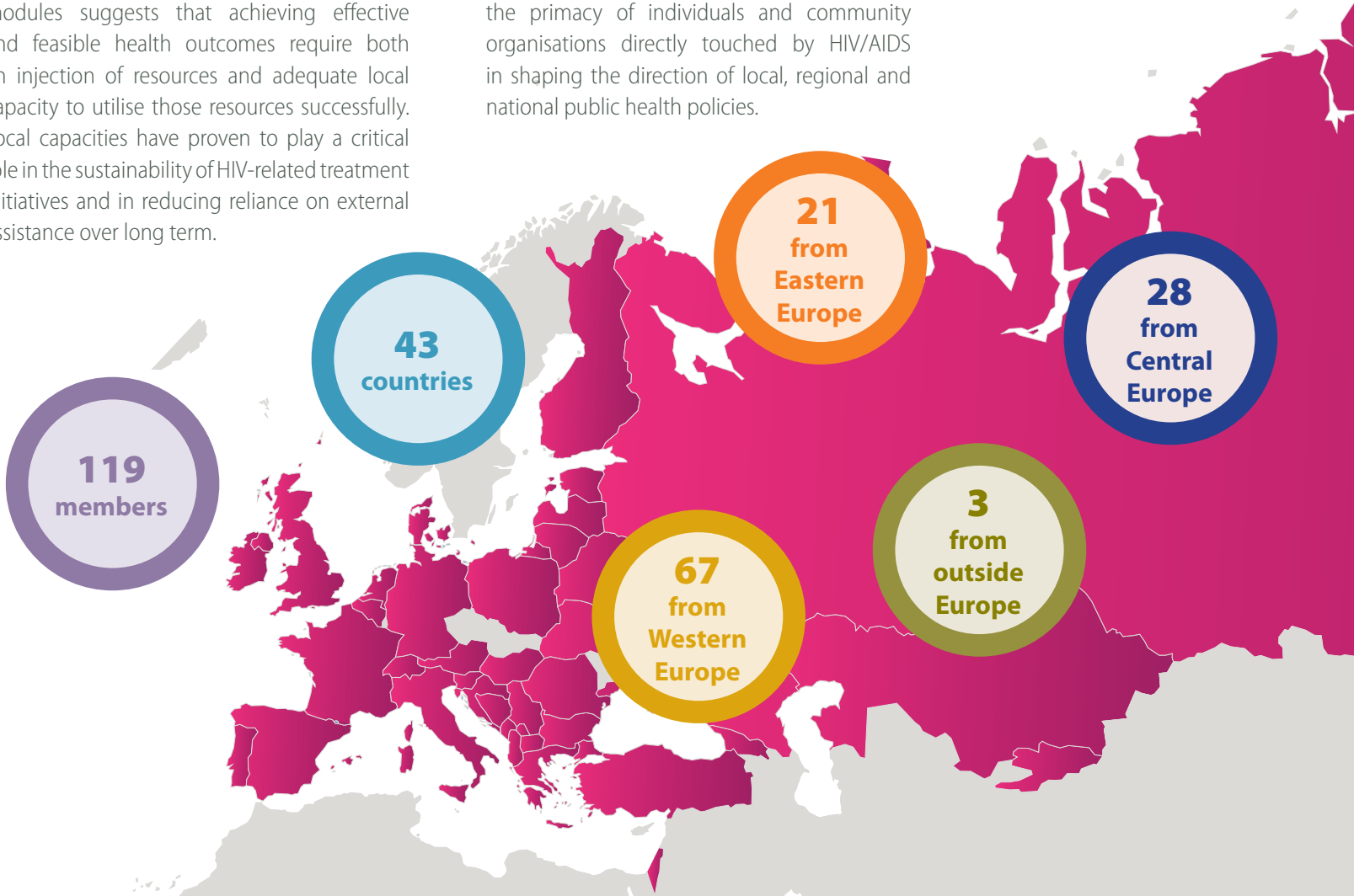
EATG's policy work is led by the **Policy Working Group (PWG)**, which brings together members engaged in advocacy at national and/or international level to ensure universal access to anti-retroviral drugs in Europe and Central Asia. It is composed of 67 members from 33 countries[1]. Almost half of the members are from Central (n=14) or Eastern Europe (n=16).

EATG's policy activities focus on treatment advocacy and in particular on equal access to early diagnosis, adequate treatment for HIV and co-infection. In doing so, it addresses barriers to early diagnosis, treatment and care, such as lack of free tests, of needed medicines and diagnostics; medicines prices; stigma and discriminatory legislation, policies and practices.

[1] *Albania • Armenia • Austria • Belarus • Belgium • Bosnia & Herzegovina • Bulgaria • Croatia • Denmark • Estonia • Finland • France • Georgia • Germany • Greece • Hungary • Ireland • Israel • Italy • Kyrgyzstan • Lithuania • Macedonia • Netherlands • Portugal • Russian Federation • Serbia • Slovenia • Spain • Switzerland • Tajikistan • Turkey • Ukraine • United Kingdom • Uzbekistan*

Within the scope of its activities, **capacity building** has become central to the work of EATG in the treatment, advocacy and prevention of HIV/AIDS and related co-infections. Launched in 2009, our experience of organising training modules suggests that achieving effective and feasible health outcomes require both an injection of resources and adequate local capacity to utilise those resources successfully. Local capacities have proven to play a critical role in the sustainability of HIV-related treatment initiatives and in reducing reliance on external assistance over long term.

Additionally, EATG capacity building activities empower local communities and contribute to forming self-sustaining collaborative networks among community-based organisations in Europe. Furthermore, EATG trainings affirm the primacy of individuals and community organisations directly touched by HIV/AIDS in shaping the direction of local, regional and national public health policies.



COMMUNITY INVOLVEMENT in HIV treatment, PREVENTION AND CLINICAL RESEARCH

"The EATG has helped the Ukraine CAB on a number of hepatitis-C-treatment related issues. They have become successful advocates around access issues".
SH – Canada

"EATG has delivered an important contribution to key discussions around TasP, especially during 2013 London conference, and has been leading on the development of a community statement".
IH – UK

"EATG's constitution around ECAB helped the MENA-CAB as a template".
TW - UK

Our achievements

EATG co-organised a community session on Treatment as Prevention on September 22 in London prior to the IAPAC meeting.

Together with NAM, EATG facilitated the development of a Community Consensus Statement on Treatment on the use of anti-retroviral therapy for preventing HIV transmission that has been launched in February 2014.

EATG developed a P**osition Paper on the proposed Clinical Trial Regulation** ,a joined open letter to members of the European Parliament (Clinical Trials Regulation – Protect public health: Choose transparency!) supported by 11 European and international organisations and their advocacy for greater transparency of clinical trials data. In December, the European Parliament and the Council of the EU came to agreement on the Clinical Trials Regulation making it mandatory for pharmaceutical companies and academic researchers to make the results of all their European clinical trials available on a publicly accessible database.

On 16 October, in the margins of the European Clinical AIDS Society Conference, EuroCoord and EATG organised a meeting with the Commission services dealing with infectious diseases and public health in the Directorate General for Research and the Directorate General for Consumer Protection and Public Health.

The EATG contributed to the EUPATI conference with a poster prepared by Tamás Bereczky and a presentation by David Haerry on the ECAB working model, which can provide guidance and best practices for a possible model of interaction between patient organizations, industry, academia and regulators. EATG largely contributed to the preparation of a catalogue and a report on successful public private partnerships (PPPs) between patients' organisations, industry and academia.

EATG published and disseminated the ECAB Review; a systematic review of the European Community Advisory Board over 15 years of treatment activism.

EATG members extensively contributed to the review of the ECRAN website (both regarding language contents and its usability) and to the assessment on material of clinical trial available on Wikipedia.

EATG organized a meeting on HCV compassionate use on June 19-20 to look for "Pathways to provide access to novel HCV compounds for people to whom they are not authorised yet, but who have no alternative treatments".

"EATG did build my capacity - Its constitution around ECAB helped the MENA-CAB as a template". TW – UK

Quote: "EATG helped to get better access to a trial in Bosnia & Herzegovina" BDB, Bosnia & Herzegovina.

Main Activities

Treatment as Prevention

Prior to the IAPAC meeting in London (Sunday September 22), a community session took place on Treatment as Prevention. After some key note lectures by Julio Montaner (The evidence base for treatment as prevention), Jane Anderson (The treatment cascade and maximising the efficiency of health systems) and Olga Stefanishina (Treatment as Prevention: Drug pricing and access issues, especially in Eastern Europe), participants did split into smaller groups to discuss a draft Community Consensus Statement. Further elaboration of the statement was done after the meeting (planned launch in 2014).

ECAB Meetings

Three HIV ECABs have been held since the beginning of 2013. The meeting guarantees the involvement of HIV patient representatives of the WHO Europe region in the process of pharmaceutical development, biomedical research and access arrangements. On the other hand ECAB meetings also guarantee that companies keep their commitment to engage and consult the community while developing and marketing their products. . Within the confidentiality terms participants of ECAB meetings are expected to use their knowledge to make informed recommendations and to give advice to the local community.

Eight pharmaceutical companies engaged in the discussion with ECAB members during HIV meetings in 2013.

During the first meeting (1-3 February) ECAB discussed the clinical trial regulation that was being under debate at the European Parliament. This first discussion led to further consultation among EATG members and to the conceptualisation of the position paper on behalf of EATG. The second meeting (5-7 April) included a discussion of the role of social sciences in ECAB, with a particular focus on possible interventions to improve mental health and reduce self-stigma among people living with HIV. The third HIV ECAB of 2013 (27-29 of September) had a focus on the epidemic and treatment in Central European countries. It was relocated from Brussels to Budapest, to bring discussion on access to innova¬tive HIV treatments in areas where the supply of drugs is limited and fur¬ther cooperation with local authori¬ties and industry is necessary. The group also reflected on the Treatment as Prevention (TasP) meeting that took place in London.

ECAB Membership

By the end of December ECAB counted 79 members from EATG within its membership and 31 external guests. Via the EATG membership 33 countries are represented including 20 countries from Central and Eastern Europe.

Main Activities

CHAARM

(Combined Highly Active Anti-Retroviral Microbicides)
Gus Cairns, steering committee member and project leader for EATG

CHAARM is a research network funded by the EC under FP7, it 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 (Gus Cairns).

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 activities and achievements starting from the second year of the project.
On Wednesday 16 October the CHAARM symposium entitled "The future of microbicides" has successfully opened the 14th edition of the European AIDS Clinical Society (EACS) conference in Brussels. The symposium was organized by the EATG in collaboration with MINERVA and chaired by Gus Cairns.

During the satellite session the presenters illustrated the activity conducted in 3.5 years of research and explained what to expect from the remaining 18 months and how the scientific community might build on the achieved results. Further information on the project and the satellite session at EACS can be found on the CHAARM website: http://chaarm.eu/

EUROCOORD

EuroCoord is a Network of Excellence established by several of the biggest HIV cohorts and collaborations within Europe - CASCADE, COHERE, EuroSIDA, and PENTA. Alain Volny-Anne is representing ECAB at EUROCOORD. This large integrated network exploits the scientific strengths of collaboration to ensure that the best, most competitive HIV research is performed.

EuroCoord has access to data from over 250,000 HIV-infected children and adults across the European continent and beyond. The multidisciplinary research undertaken by the network addresses key areas aimed at improving the management and life of HIV-infected individuals, whilst allowing differences within sub-groups to be explored.

On 16 October, in the margins of the European Clinical AIDS Society Conference, EuroCoord and EATG organised a meeting with the Commission servic¬es dealing with infectious diseases and public health in the 'Directorate General for Research and the Directorate General for Consumer Protection and Public Health'. The participants examined the achievements of EuroCoord; interaction between research and civil society; new challenges in HIV research to be addressed in coming years; challenges in Eastern Europe; addressing emerging clinical questions in hepatitis co-infection and reducing inequalities.

Within the framework of WP 14 of Eurocoord, the **aMASE project** took a launch in 2013 (see also page 20).

EUPATI

EUPATI is an IMI-funded consortium project, led by the European Patients' Forum, to educate patients and the lay public about how medicines' R&D works. A consortium of 29 organisations is developing training courses, educational toolkits and a web-based library to provide objective and credible information about medicines R&D and how patients can get involved. EUPATI will cover seven languages in 12 countries. The consortium can proudly look at the project's first year. All objectives have been achieved and all planned deliverables are about to be completed. EATG is involved in the project as co-leader of WP7 and partner of WP2, WP4 and WP6. With its partners, EATG is leading on the development of application packages, guidelines for applicants and selection criteria for future participants of the Academy.

The main activity of work package 7 (WP7), which is re¬sponsible of the sustainability element of EUPATI consortium, was the preparation of a catalogue and a report on successful public private partnerships (PPPs) between patients' organisations, industry and academia. The catalogue provides references and examples of successful collaborations that can be used as guidance for future partnerships, addressing the need for more active involvement of patient experts in medi¬cines R&D.

http://www.patientsacademy.eu/index.php/en/joomdoc/259-ppp-report/file

The first EUPATI conference entitled "EUPATI: a vision for 2020" has been held in Rome

on 19 April and focused on 3 main topics: patient involvement in medicines research and development, building competence and knowledge in medicine research and development. The EATG contributed to the conference with a poster prepared by Tamás Bereczky and a presentation from David Haerry on the ECAB working model, which can provide guidance and best practices for a possible model of interaction between patient organizations, industry, academia and regulators.
http://www.eatg.org/eatg/Scientific-Research/Projects/The-European-Patients-Academy-on-Therapeutic-Innovation-EUPATI

During the annual face to face meeting of WP7, which took place in Berlin on the 7th of November, the activities for the next year were discussed. In 2014 WP7 will progress towards the creation of guidelines for interaction between patients' organizations, regulators, health technology assessment and ethics committees, and the provision of recommendations regarding the implementation of new learning methodologies.

The work carried out within WP7 is the result of a close and intense collaboration among three main partners of the EUPATI consortium: patients' organizations, industry and academia. EATG is co-leading WP7 together with Bayer. David Haerry is the project leader for EATG within the EUPATI project.

NEAT - European AIDS Treatment Network

NEAT (http://www.neat-noe.org) is a network of Excellence funded by the European Commission under the FP6 Programme. Its mission is to strengthen European HIV clinical research capacity. The NEAT project was concluded in June 2013 and the main EATG contribution of the last year was the publication of the ECAB Review (see 3.5 The ECAB Review). Nikos Dedes was appointed as EATG project leader for NEAT.

ECRAN – European Communication on Research Awareness Needs project

The ECRAN project (www.ecranproject.eu) is designed to develop a portfolio of open educational resources for the general population about the challenges raised by independent clinical research. ECRAN provides a multi-lingual website. Full contents and all navigation and searching tools are provided

in the 6 most common languages (English, French, Italian, Spanish, German and Polish). Selected contents are available in 17 other European languages (Bulgarian, Czech, Danish, Dutch, Estonian, Finnish, Hungarian, Gaelic, Greek, Latvian, Lithuanian, Maltese, Portuguese, Ro¬manian, Slovak, Slovenian and Swed¬ish). A short movie to inform the general population on how clinical trials are developed and conducted is available in 23 versions on the ECRAN website (http://www.ecranproject.eu/en/node/10). ECRAN also performed the review of the existing Wikipedia pages on clinical trials and related issues.

The EATG, represented by **Brian West** and **Nikos Dedes** is a non-leading partner in 4 work packages of the project: Creation of a multi-language website, Production of an animated film on clinical trials, planning and development of communication tools and development of communication material. EATG members extensively contributed to the review of the website (both regarding language contents and its usability) and to the assessment on material of clinical trial available on Wikipedia.

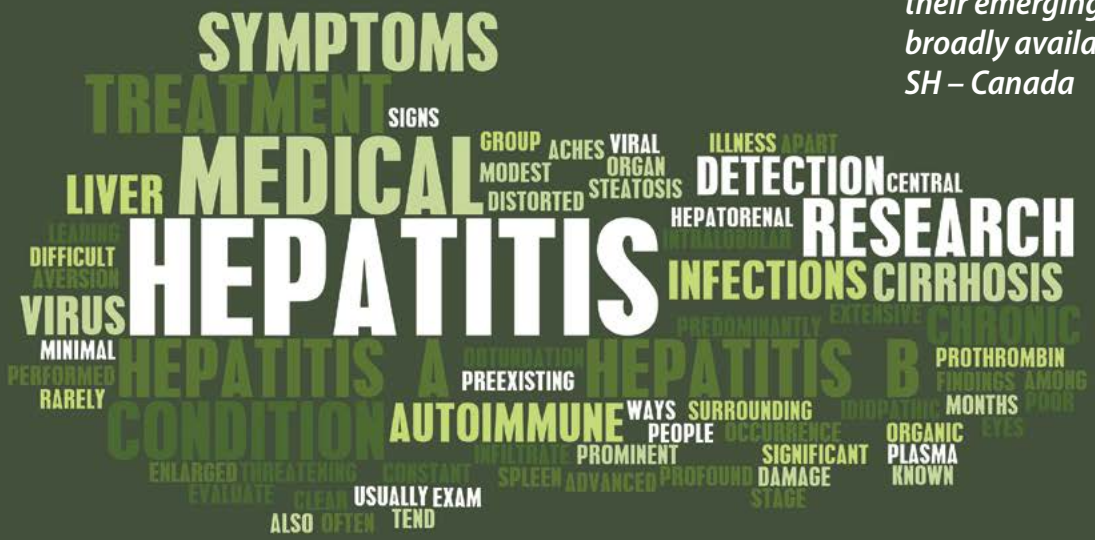
The ECRAN consortium met in Milan in September to discuss the activities regarding the last part of the project. On the 21st of May 2014 a final event will be organized in Luxembourg to present the outcomes of the project and their implications for the general population and specific groups.

Protocol reviews

An important expertise of ECAB is to review clinical trial protocols, informed consent sheets, package leaflets and **European public assessment reports** from the PLHIV Community's perspective and needs. The main protocol inputs were taken into account by the trial sponsors and the EMA and the protocols and ICFs were adapted accordingly. Nine protocols were reviewed from the beginning of 2013.

Hepatitis C and TB co-infections

The knowledge gained from the stakeholders meeting in Brussels on compassionate access helped me to push pharmaceutical companies in Canada to make their emerging HCV therapies more broadly available.
SH – Canada



Our achievements

EATG managed to push for co-infected trials via the Sitges VI multi-stakeholders meeting. The meeting considered the regulatory approach towards special populations, particularly people with HIV/HCV co-infection, children, post-transplant patients; and people with decompensated liver disease.

The compassionate use meeting prior to the thematic Hepatitis C meeting in June 2013 helped to push pharmaceutical companies in Canada to make their emerging HCV therapies more broadly available.

EATG contributes to TB online with six other organisations: Community Media Trust, Treatment Action Group, Treatment Action Campaign, European AIDS Treatment Group, South Africa Development Fund and HIV i-Base.

TB Online is a website for activists, patients, health workers and researchers to disseminate knowledge and promote advocacy to end the worldwide epidemic of tuberculosis.

The site is run by the Global Tuberculosis Community Advisory Board (TB CAB) and is dedicated to increasing community involvement in TB research and to mobilizing political will to develop and make available TB diagnostics and treatments.

The TB CAB is comprised of research activists from all over the world, who are extensively involved in HIV and TB research networks.

During 2013 TB online was consulted by 85.549 visitors for a total of 122.764 number of visits. The website was mostly consulted during the first half of 2013, with a number of visitors varying between 7069 in February and 8770 in April.
Anna Balkandjieva contributes to the contents of TB Online on the Behalf of the EATG.

http://www.tbonline.info/

Thematic ECAB on tuberculosis

The third ECAB meeting (May 17-19) was a thematic meeting on tuberculosis (TB) and HIV co-infection organized by Wim Vandevelde. The purpose of the meeting was to better inform the ECAB members and HIV community advocates on TB diagnosis, treatment, care and research advocacy. Representative from WHO, researchers and clinicians, community-based organizations, and pharmaceutical companies discussed TB drugs, diagnostics development and access and identified key advocacy priorities. Three companies attended the TB ECAB meeting. A report on the meeting has been produced and is available on the EATG website: http://www.eatg.org/gallery/169941/Report_TB_ECAB_MAY13.pdf

The Sitges meeting pricing and access was really needed and EATG managed to push for co-infected trials.
DK - UK

HEPATITIS C and TB co-infections

Thematic ECAB meetings on hepatitis C

The work of EATG in the hepati¬tis C field in the last years has moved from being primarily based on clinical trial design to advocacy for increased access and support for off-label use of newer interferon-free hepatitis C drugs for those who have been left behind.

EATG organised two thematic HCV meetings in 2013: one in June (21-23) and a second one in December (13-15). In total 6 companies engaged in the HCV ECAB debate in 2013.

Pre-meeting on compassionate use

The HCV ECAB in June was anticipated by a multi-stakeholder meeting on compassionate use programmes for HCV patients named "Pathways to provide access to novel HCV compounds to people to whom they are not yet authorised, but who have no alternative treatments" (19-20 June).

The Invited participants were representatives from community based organizations, European and local regulatory bodies, clinicians, researchers and pharmaceutical companies. A report on the meeting has been produced and is available on the EATG website: http://www.eatg.org/gallery/169382/Report-Compassionate%20use%20meeting.pdf


EATG European AIDS Treatment Group

Meeting report

International multi-stakeholders meeting
June 19-20, 2013-Brussels, Belgium

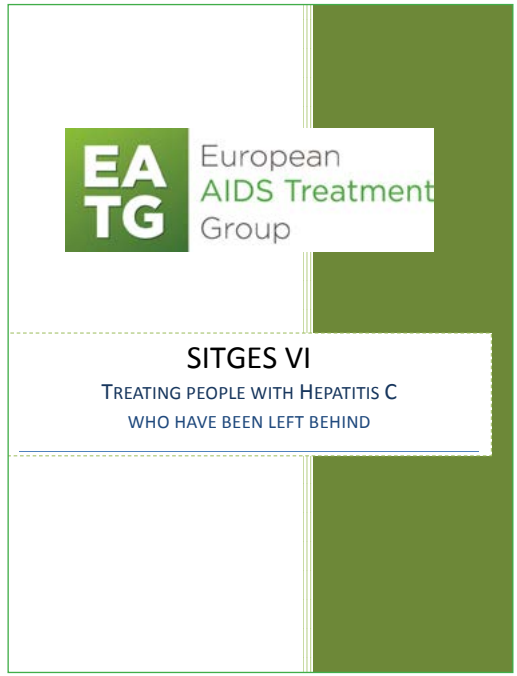
"Pathways to provide access to novel HCV compounds to people for whom they are yet not authorised, but who have no alternative treatments"

By Svilen Konov

Main Activities

Sitges VI

The Sitges VI meeting (October 4-6 2013) considered the regulatory approach towards special populations, particularly people with HIV/HCV co-infection, children, post-transplant patients; and people with decompensated liver disease. Due to high HCV prevalence, people who inject drugs (PWID) were highlighted as a special population in need of further education, access to treatment and inclusion on hepatitis C clinical trials.



Summaries on safety, efficacy and tolerability and relevance in HIV/HCV co-infection for direct acting antivirals (DAAs) nearing regulatory approval were given, with information on addressing issues around access and practical concerns, particularly evolving information on drug-drug interactions, adverse events, and overall DAA optimisation in addition to optimising regimens for genotypes 1, 3 and 4.

Unanswered questions about hepatitis C treatment were considered, pertaining to the disease burden from chronic HCV in co-infected patients on early antiretroviral therapy with no relevant fibrosis; the difficulty of treatment in genotype 3; the potential role for pre- or post-exposure prophylaxis in hepatitis C; and the parameters needed to inform duration and specificity of hepatitis C treatment regimens for the clinician.

A report on the meeting has been produced and is available on the EATG website: http://www.eatg.org/gallery/169548/SITGES%20VI.pdf

In 2013 Svilen Konov has been the Hepatitis-Consultant, responsible of the organization and coordination of all the activities related to HCV on the behalf of EATG.

Training for Russian communities of people living with HIV/AIDS

On 29-31 March 2013, EATG organised the training "Integrated Approaches to the Treatment of HIV/AIDS and Related Co-infections in the Russian Federation". 27 participants representing patients, members of organisations and communities that work with HIV-positive patients, doctors and health care providers were trained by 3 EATG trainers: Stephan Dressler, Sergey Golovin, Svilen Konov. The event focused on the best practices of HIV/HCV/TB treatment and care; dialogue between health care providers and patients and building liaisons with local Russian HIV community organisations.

Several small group workshops and discussions organised during the training revealed a persistent lack of communication and collaboration between doctors and patients. Guest speakers shared "success stories" of joint projects between local municipalities and HIV-community organisation on adherence to treatment of TB in the cities of Tomsk and Chelyabinsk. During the last day of the training, a comprehensive Questions and Answers session initiated a 3-hour long discussion among the doctors and patients on how to foster collaboration within their communities.

The participants were trained on how to pass newly acquired knowledge to colleagues in their home organisations and how to diffuse this knowledge among other community-based organisations dealing with treatment and prevention of HIV/AIDS and related co-infections. EATG allocated funds to support 4 post-training follow-up activities:

1. Patient School: Treatment of HIV/AIDS and Related Co-infections Among Female Prisoners in Khakasiya (three 1-day trainings for female prisoners in Abakan);
   2 trainings for a total of 53 female prisoners;
2. Integrated Approaches to the Treatment of HIV/AIDS and HCV in Altai Region (2-day training for patients from Altai region);
3. Increasing Awareness on the Treatment and Prophylaxis of HIV and HCV/TB among IDUs in Moscow and Moscow Region (two 1-day trainings in collaboration with AFEW Moscow office);
   4 seminars for a total of 51 participants (17 women and 34 men)
4. Patient School: Treatment of HIV/AIDS and Related Co-infections Among Prisoners in Tatarstan (seven 1-day trainings in Tatarstan)
   4 seminars for a total of 52 participants (31 women and 21 men)

EARLY testing in key vulnerable populations

EATG has taken a leading position in the promotion of the testing week at a European level. This initiative was supported by many organisations and stakeholders.
GMC – Italy

The HIV in Europe initiative focusing on early diagnosis and early care

EATG continued to serve as Advocacy Secretariat of the HIV in Europe initiative: 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.

EATG has also supported the implementation of the European Testing Week at the end of November (culminating on World AIDS Day) by organising testing in front of the European Parliament in collaboration with Médecins du Monde/Doctors of the World.

EATG organised sessions on the developments in HIV testing at the EU Civil Society Forum and Think Tank meetings 9-11 December. The session served as a debriefing of the European Testing week. The results of HIV in Eu¬rope research on testing according to indicator conditions and the Cobatest project were also presented. The pres-entations were followed by a discus¬sion on implications for future work

Our achievements

In October, EATG reached out to members of the European Parliament and other partners regarding amend-ments to the EU legislative proposal on in vitro diagnostic medical devices. EATG urged Members of the European Parliament, including the rapporteur, to vote down amendments resulting in the classification of HIV self-testing kits among the class of devices re¬quiring medical prescription. As a result the most problematic amendments were indeed voted down.

EATG actively promoted **the European testing week** and increasing screening opportunities at a European level. EATG organised a testing activity in front of the Parliament on November 26.

EATG organised sessions on the developments in HIV testing at the EU Civil Society Forum and Think Tank meetings 9-11 December. The session served as a debriefing of the European Testing week. The results of HIV in Europe research on testing according to indicator conditions and the Cobatest project were also presented. The presentations were followed by a discus¬sion on implications for future work.

HIV in Europe
Working Together for Optimal Testing and Earlier Care

COMMUNITY involvement in treatment advocacy

Our achievements

The EATG initiated a 'call to the European Commission and European Leaders to re-affirm their Leadership and Commitment on HIV/AIDS, both inside and outside of the European Union, by Approving a new Strategy and Action Plan on HIV/AIDS for the post 2013 period' was endorsed by 200 stakeholders, including national, European/ international NGOs and networks, researchers, doctors, professional associations, medical society, national parliamentarians and members of the European Parliament.

EU HIV/AIDS Civil Society Forum (CSF) and Think Tank

The EU HIV/AIDS Civil Society Forum (co-chair on behalf of EATG: Anna Żakowicz)

At the end of her term (end 2013) Anna was replaced by Tamás Bereczky

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 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. The CSF includes about 40 organizations from all over Europe.

The CSF met once during this period (May 27) and served as preparation for the European Commission-UNAIDS conference on "the right to life, the right to health". EATG participated at this conference. Luis Mendão gave a key note speech and Raminta Stuikyte spoke on the funding gap in Eastern Europe.

In April, following signals of a weakening of EU leadership on HIV, EATG coordinated a call "Call to the European Commission and European Leaders to re-affirm their Leadership and Commitment on HIV/AIDS, both inside and outside of the European Union, by Approving a new Strategy and Action Plan on HIV/AIDS for the post 2013 period". The call was endorsed by over 200 stakeholders, including national, European/ international NGOs and networks, researchers, doctors, professional associations, medical society, national parliamentarians and members of the European Parliament.

EATG was pleased to hear Commissioner for Health Borg's announcement that an evaluation of the Commission Communication on HIV would be undertaken and that he would see to the adoption of a policy framework on HIV by the end of his term in October 2014. Moreover, it was informed that the Commission is working on an interim action plan for 2014 to avoid a policy gap. In role as co-chair of the EU Civil Society Forum on HIV/AIDS it will facilitate community contribution to the evaluation and the drafting of the action plan.

EATG took part in the EU HIV Think Tank meeting that took place on May 29 discussing latest treatment access date in Europe and new global WHO HIV/AIDS treatment and care guidelines.

"Although the PWG meeting in Riga happened in 2011, the decision-takers are still aware that external experts may be summoned again".
SK – Latvia

"EATG made it possible to publish a very welcome new booklet in local language HIV and sex, in a frame of COPE project".
MS - Slovenia

Empowerment

Our achievements

EATG facilitated a meeting that brought together – for some participants for the first time - young activists from different regions and countries in Eastern Europe, allowing some activists to speak and get engaged. It was confirmed by many participants that this initiative answered an important need.

EATG did enable local partners to organise training to their networks so that knowledge was immediately transferred to other activists and stakeholders, often in more difficult to reach regions.

Training "Integrated approaches to the treatment of HIV/AIDS and related co-infections"

The Russian Federation has the largest HIV epidemic in Europe and accounts for two-thirds of all cases of HIV infection in the Eastern Europe and Central Asia region. Officially 3.8% of new tuberculosis cases in the Russian Federation occur in individuals who are HIV-positive, representing the growing challenging of tuberculosis/HIV co-infection. Eastern Europe also has high rates of HIV/HCV co-infection, which keeps rising – up to 80% among people living with HIV and seeking treatment in Estonia and Ukraine and over 90% in samples tested in Russia.

EATG provided training in St Petersburg (29-31 March 2013). A total of 138 applications were received by the published deadline. 15 participants attended the training provided by Stephan Dressler, Svilen Konov and Sergey Golovin, focusing on best practices in HIV/HCV/TB treatment and care; on dialogue between health care providers and patients; on solidarity with PLHIV. The training was designed to promote a share of experiences between PLHIV and health care providers giving a special focus to doctor-patient relationship.

As part of this project EATG also reserved money to support four post-training follow-up activities:

1 Two trainings on HIV and HCV/HIV and TB treatment among Female Prisoners in Khakasiya;
2 Two trainings on HIV and HCV/HIV and TB treatment among Prisoners in Tatarstan;
3 Two trainings on HIV and HCV/HIV and TB treatment among IDUs in Moscow Region; and
4 One training on HIV and HCV Treatment in Altay for Former IDUs.

Training "Youth in positive action: engaging and empowering young people for HIV/AIDS treatment, care and prevention"

Young people aged 15-26 remain at the centre of HIV/AIDS epidemic in terms of rates of infection and vulnerability. Young people are disproportionally affected with HIV/AIDS and witness the smallest number of programmes that promote healthy adolescent development and provide young people with age-appropriate knowledge and tools to make informed choices.

EATG – in collaboration with the East Europe and Central Asia Union of People Living with HIV (ECUO) – provided training for young people

"EATG did build my capacity - Excellent and useful update/ information on new treatments, and negotiations with drug companies".
IH - UK

"EATG helped to provide more information which is crucial because of the complicated situation in my country. EATG helped young people from the region to assert them better".
BDB - Bosnia & Herzegovina

Main Activities

and health care providers working with them. With this training called "*Youth in Positive Action: Engaging and Empowering Young People for HIV/AIDS Treatment, Care and Prevention*" EATG aimed at including young HIV-positive people, their needs (both medical and psychological) into public health care discourse in the countries of the former USSR. Out of over 150 applications from 20 different countries in East and Central Europe, 20 young activists from Belarus, Ukraine, Russia, Uzbekistan, Kazakhstan, Kyrgyzstan and Romania came together in Kyiv, Ukraine from 19-21 July 2013 to discuss specific problems for adolescents living with HIV and to exchange ideas and their experiences.

They were trained by Tamás Bereczky, Damian Kelly and Svilen Konov. In different sessions the trainees learned about HIV treatment and side effects, co-infections, status disclosure, sexual health and advocacy. Case studies were actively debated during a workshop session and three very brave young people shared their personal stories about their life with HIV and answered questions of their peers. During the three very exciting and interesting days of training participants took the opportunity to learn, to get inspired and to share and made this training a success story.

Our local partner East Europe and Central Asian Union of PLWH provided valuable input. After the training, EATG supported a follow-up project.

Following the training, EATG decided to award post-training grant to the Zaporizhya Regional Charitable Foundation "Gender Z" to organize a three-day training "School of Tolerance." The School took place in Zaporizhya, Ukraine on 29 November – 01 December 2013.

The objective of the "School of Tolerance" was to contribute the process of building tolerance and providing accurate information to young students of three largest universities in the region. As these students are likely to become future opinion-makers in Ukraine who will form societal opinion on such issues as HIV/AIDS, homosexuality, greater human tolerance, stigmatization and discrimination, Gender Z put

special emphasis on recruiting the trainees from the faculties of journalism and sociology.

The training covered the following topics:
Day 1: Tolerance and Acceptance of Diversity/ Homosexuality and Heteronormativity

The training discussed the construction of stereotypes, false perceptions and social exclusion in Ukraine. By analyzing TV ads and commercials, linguistic peculiarities, the trainers showed the developments in Ukraine on the construction of images of "man-strong/woman-weak" dichotomies and how these constructs limit the access to services and opportunities for certain groups. The trainees learnt about the differences between such categories as sex and gender, stigma and discrimination, tolerance and acceptance and 'mirror ceiling.' During the second half of the day, the participants worked in small groups reviewing news reports, press releases and short TV ads for the presence of implied, implicit and explicit discriminatory elements in them. The task was completed by re-drafting and improving given texts to make them more objective.

The training started with the review of the history of the movement for civil rights and liberties in Europe and the US. Following the discussion, the trainers explained how the norms of heteronormativity are used to depict all other manifestations of sexual orientation as 'deviant and pervert.' The presentations explored how stigmatization and discrimination of certain groups, particularly MSM and IDUs leads to detrimental outcomes, particularly in public health sector in Ukraine. At the end of the day

Day 2: HIV/AIDS and Societal Responsibility
The training began with the assessment of knowledge of participants on HIV/AIDS. The exercise revealed that most participants had basic understanding of HIV (difference between HIV and AIDS, vulnerable groups). At the same time, only 2 participants were able to differentiate false and accurate statements about HIV and discrimination (for instance, transmission routes). After the lunch break, the participants were assigned in small groups. Each group received a case study asking them to examine real-life story of PLWH for the presence of discrimination and how the reporting on the story could be improved. The task aimed at using the knowledge from Day 1 and Day 2 to prepare new report.

At the end of the day, the participants were split into three groups. The task was to prepare a short video on one of the assigned topics:
Topics 1: HIV is not a verdict.
Topic 2: Let others be as they are.
Topic: Is Ukraine ready for LGBT movement.

"EATG is doing well within its current strategy. It can do more outside Europe".
TW - UK

"EATG helped to increase the AGIHAS authority even more. EATG also helped to increase PLWHA treatment literacy ».
SK – Latvia

The objective of the video was to show prevailing societal misconceptions and misperceptions on HIV/AIDS, on sexual orientation and on discrimination towards marginalized groups. The video would incorporate the knowledge from the trainings' presentations and case studies.

The "School of Tolerance" is the only existing activity of this kind in Ukraine. In light of an increasing discriminatory attitude towards LGBT and PLWH, chiefly driven by the lack of accurate knowledge rather than by inherent societal xenophobia, the School of Tolerance may become one of the tools for creating greater awareness, tolerance and acceptance of diversities of the Ukrainian society. A series of all-Ukrainian Schools of Tolerance was proposed as one of the initiatives to be implanted in 2014.

Community-Based System in HIV Treatment (CoBaSys)

EATG attended the Final Meeting of stakeholders and partners of the project "Community-Based System in HIV Treatment" held in Tanzania during 07-08 April 2013. The meeting summarised the impact that the project had on empowering African communities affected by HIV. During the project's duration (2009-2013), EATG provided its input on topics such as fundraising for community-based projects, capacity building for local HIV communities, empowering communities for advocacy. Several partners of the CoBaSys project valued our contributions on building relations with the European Union and its policies on HIV.

EATG will continue to represent and defend treatment-related interests of PLHIV worldwide, but our focus will remain on activities in Europe, where we have a better grasp and stronger impact for HIV communities.

EATG Training Academy
STEP-UP: Skills Training to Empower Patients

EATG Training Academy STEP-UP

The EATG Training Academy 'STEP-UP' (Skills Training to Empower Patients) is a modular training programme designed to:

- respond to the training needs of (future) community activists and health care providers on HIV and co-infections
- provide education on HIV/AIDS treatment, care and prevention related topics;
- contribute to personal development and training of people who have an aspiration

and realistic potential to become future HIV treatment activists and advocates.

After their graduation, the trainees will be better equipped to design action plans for the best practices of treatment and care of people living with HIV/AIDS and related co-infections in their local communities in Europe and Central Asia.

The launch and the first module of the training academy took place in Brussels, linked to the 14th European AIDS Society Conference (EACS) in Brussels (13-16 October 2013). 19 trainees from 15 countries attended the meeting. As the treatment of HIV/AIDS and related co-infections remains the most crucial issue in the current HIV and global public health discourse, Module 1 topics dealt with the introduction to the treatment-related issues. The overall objective of Module 1 was to "level-up" all trainees to the same level of knowledge on medical treatment procedures that are available for HIV-positive patients. In addition, the trainers discussed treatment and prevention of HCV and TB as well as the treatment options that are in the pipeline. This was done in order to familiarise the trainees with the diversity of challenges that they may be confronted with as future treatment activists in their work. Additionally, this "sneak preview" of HIV/HCV/TB treatment, care and prevention gave an opportunity for the trainees to get sense of the future topics that would be discussed during the next four modules.

The benefits of the participation in EACS conference was highly remarked by both the trainees and the trainers. The largest impact that the conference had on the trainees was the introduction of HIV treatment guidelines. As noted by some participants, in their home countries HIV treatment guidelines per se do not exist or are very outdated and rely on the findings and recommendations from trials of 1990s. Most notably, the participant from Uzbekistan reported that after returning to his country, he held several educational sessions at the medical university where he is currently studying on the contemporary treatment guidelines. This was received with immense enthusiasm as most healthcare providers and medical students rely on general knowledge on infectious diseases when dealing with HIV-related matters. At the request, EATG provides several dozens of hard copies of the treatment guidelines in Russian for local hospitals in Uzbekistan.

During the conference, several trainees teamed up for a joint tour around posters to get acquainted with the most recent and existing initiatives and developments. The group comprised of three medical students and four community activists from the UK, Uzbekistan,

Main Activities

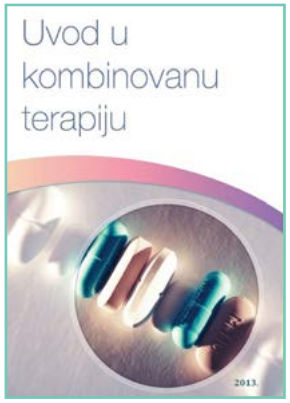
"EATG made it possible to publish a very welcome new booklet in local language HIV and sex, in a frame of COPE project".
MS – Slovenia

Spain, Armenia, Albania, Russia and Ukraine. The added value of such interaction is that trainees with different backgrounds informed each other about the areas, in which they are experts and communicated technical information in user-friendly terminology to their follow colleagues. For instance, several posters that addressed the HIV/HCV treatment in pipeline contained very scientific information, which was relevant for the treatment activists from Ukraine and Russia but who could not understand the medical aspects of the poster. Two trainees with medical background explained the poster to the community advocates in detail ensuring that the information can be understood and communicated in a simplified version.

COPE

EATG supported four projects through COPE, our Continuous Patient Education project from Armenia, Portugal, Serbia and Slovenia:
"Safe sex: straight talk" (International HIV/AIDS Alliance Ukraine) into Armenian
"Introduction to Combination Therapy" (i-Base) into Portuguese and Serbian

"HIV and sex" (NAM) into Slovenian
A big thank you to the organisations that once again make their publications available for translation into other languages!



Community feedback sessions at conferences

The European AIDS Treatment Group regularly organises community feedback sessions on key findings and results of the most important HIV / co-infection conferences. The community feedback sessions allow treatment activists that are new or not familiar with conferences to better understand key messages from the conference that can be shared with their local colleagues.

EATG organized a feedback session during the 14th Conference of the European AIDS Clinical Society (EACS). The meeting was attended by representatives of the community of people living with HIV (PLHIV), EACS, and also by participants of the EATG Training Academy STEP-UP. A total of approximately 45 people participated in the meeting.

ACCESS to affordable treatment and care

EATG helped to have the introduction of Truvada in Hungary and to get political support.
DB - Hungary

EATG has helped us to get better access to a trial in Canada.
SH - Canada

Our achievements

EATG did speak at the European Parliament organised session on "Getting to zero": Addressing societal challenges of HIV patients, which was organized by madame Mathieu-Houillon to discuss community needs and barriers related to testing, treatment and care in Europe.

EATG has advocated for a new European Commission Communication as policy framework. It welcomes the update of the action plan as an interim measure to avoid a policy gap from 2013. EATG facilitated input of civil society in the process as co-chair of the HIV Civil Society Forum

Access to medicines

EATG took part in steering committee and the conference on access to medicines in times of economic crisis at the European Parliament on 16 May. Raminta Stuikyte spoke on the situation of 2004-2007 member states, innovative meds and high prices for small budgets. The conference was organized by the European Public Health Alliance, in collaboration with the European Association of Hospital Pharmacists, EATG, Health Action International Europe, and European Pharmaceutical Group of the EU (Community Pharmacists), Transatlantic Consumer Dialogue Partnership (http://www.a2meurope.eu/index.php?id=home).

This event was not a one-off event but a part of a longer term initiative of a few NGOs, among which EATG, to inject health related concerns on the EU's agenda when dealing with the crisis and public deficit reduction. It brought together academics, policy makers, politicians, professionals working delivering health care locally, other civil society representatives, and pharmaceutical companies to discuss measures to ensure access to affordable medicines and respective roles.

In July, EATG joined the European Public Health Alliance, Collectif Interassociatif Sur la Santé (CISS), Doctors of the World, Health Action International – Europe (HAI Europe), Salud por Derecho - Right to Health Foundation and Trans-Atlantic Consumer Dialogue (TACD) to draft and send a joint statement to EU policy-makers asking them to avoid certain short-term measures aimed at reducing budget deficits, especially those deteriorating standards of care and equity in access to treatment. Instead, the organisations advocate for measures addressing dysfunctions in the health system and market failures resulting in the high price of certain life-saving medicines, e.g. for HIV, Hepatitis C and Tuberculosis.

Being part of ECAB has made the communication with local representatives much better and made them more careful at a local level.
DU - Turkey

EATG has showed a unique strong position as European community in asking for more affordable prices.
GMC – Italy

"Although the PWG meeting "Towards Universal Access to HIV Treatment and Care in Europe" in Riga happened in 2011, the decision-takers are still aware that external experts may be summoned again".
SK - Latvia

HUMAN RIGHTS and vulnerable populations

Our achievements

In May, EATG took an active part in the conference organised by UNAIDS and the European Commission on HIV and Human Rights. Luis Mendão was a key note speaker and Raminta Stuikyte spoke about challenges following the programmed exit from Global Fund from the Region. At the event, the Commission committed to a new policy framework on HIV/AIDS. This followed a call for a renewed political commitment in Europe, which was coordinated by EATG and signed by 200 stakeholders. At the conference, EATG highlighted stigma, access to affordable medicines and access to healthcare for all irrespective of residence or insurance status. EATG member, Luis Mendão was subsequently invited to speak on these issues at the session organised by the European Commission in European Health Forum in Gastein, Austria.

In June, EATG became a member of the Platform for International Cooperation on Undocumented Migrants, a network organisation, which seeks to advance respect for the human rights of undocumented migrants within Europe. EATG will provide perspectives from the HIV field and will contribute to PICUM's work to ensure access to healthcare for undocumented migrants. ►►

►► EATG managed to include the panel "Health in the LGBT world" within the Human Rights conference of the 3rd World Outgames (WOGA2013), the major LGBT sports event, which took place in Antwerp in July-August this year. We also managed to add health and HIV-related topics to the final Antwerp Declaration.

After interference by local Greek organisations, supported by EATG, a decision to re-introduce mandatory testing in Greece has been suspended while a new regulation on communicable disease is being prepared.

Efforts to overcome Australia's restrictions were discussed at the IAS conference in Kuala Lumpur, especially as it will host the 2014 International AIDS Conference in Melbourne. EATG followed up with a letter to the IAS.

In October 2013, EATG published a position paper on prosecutions for HIV non-disclosure, exposure and/or transmission recommending that the criminal law should only be used in extremely rare and unusual cases where HIV is maliciously and intentionally transmitted. It also endorsed the UNAIDS guidelines. The paper was translated into Russian.

That same month EATG and AIDS Action Europe also sent a request as chairs of the Civil Society Forum to the up¬coming Italian EU presidency in the second half of 2014 to convene a ministerial event to review the implementation of the Dublin Declaration and renew the European Commitment to fight HIV. The European Commission reacted positively to the request but we are still waiting for an answer from the Italian presidency planning team.

"The EATG training gave me the idea to organize a project including a component of a positive voice, with people who want to be open about their status, to better understand and feel the life, stigma and discrimination of HIV positive people in Kyrgyzstan".
NIK – Kyrgyzstan

"EATG supported a common statement with EACS on gay rights in Russia".
GMC – Italy

Main Activities

Men having Sex with Men (MSM)

EATG became an associate member of ILGA-, a global federation of groups campaigning for equality for Lesbian, Gay, Bisexual, Transgender and Intersex people. Participating in the European Region, EATG will try to get involved in their activities, collaborate and work together to include HIV issues in their agenda.

EATG coordinated a satellite session during the 2nd Conference on HIV infection among hidden groups – namely men who have sex with men (MSM) and commercial sex workers on 25-26 March 2013 in Lisbon Portugal. The session, introduced by PWG co-chair Peter Wiessner, aimed at presenting real experiences from various actors working with migrant MSM and sex workers. Within the current legal framework in many European countries, migrants very often need to deceive authorities to access health system benefits, as otherwise their access to treatment and prevention services remains restricted for them due to their legal status or socio-cultural background.

The meeting was closed by Giulio Maria Corbelli who highlighted how many lies there are in migrant MSM lives: they need to lie in order to get access to health services, to lie to get treatment and to lie within their communities.
With the support of the organisers EATG managed to include the panel "Health in the LGBT world" within the Human Rights conference of the 3rd World Outgames (WOGA2013), the major LGBT sports event, which took place in Antwerp in July-August this year. Giulio Maria Corbelli acted as facilitator of the session. Michael Meulbroek and Matthew Weait and some other panellists talked about different issues affecting health in the LGBT community such as HIV criminalisation, prevention, mental health, access to healthcare and treatment for migrants, sex workers and MSM. We also managed to add health and HIV-related topics to the final Antwerp Declaration.
On 6 November, representing EATG and HIV in Europe, Ferenc Bagyinszky spoke at the European Parliament hearing "Achieving the right to health of LGBTI people". The event organised by UNAIDS and the LGTBI intergroup in the European Parliament addressed HIV and discrimination in the health sector towards LGBTI, discrimination of persons living with HIV and the role of the stakeholders including the gay movement in addressing the continuing HIV epidemic. This initiative was part of an effort to remobilize the LGTBI movement to address HIV and stigma.

HEALTH

We should create environments that enable effective integration and participation of people with physical or mental illness within the LGBTI community and we should actively support and organise prevention and solidarity activities and reach out to health organisations supporting people living with sexual transmitted diseases. Transgender and gender-non conforming individuals and categories (ICD, DSM) related to sexual orientation should be removed from the international statistical classification of diseases and related health problems, preferably during the eleventh revision;

Migrants

In May, EATG organised a round-table discussion with the European Standing Committee of Doctors, Médecins du Monde, European Public Health Alliance and Platform for International Cooperation on Undocumented Migrants which examined strategies to enable access to ARVs and other affordable medicines for undocumented migrants. Participants discussed strong and convincing arguments for providing access to ARVs to uninsured and undocumented migrants and to analyse failures from the past. Last but not least, participants discussed possible collaborations, policy strategies and concrete steps forward.

In June, EATG became a member of the Platform for International Cooperation on Undocumented Migrants, a network organisation, which seeks to advance respect for the human rights of undocumented migrants within Europe. EATG will provide perspectives from the HIV field and will contribute to PICUM's work to ensure access to healthcare for undocumented migrants.

aMASE Community Survey

EATG is a partner within the aMASE project. EATG is a partner within the 'advancing Migrant Access to health Services in Europe (aMASE) project', supporting the coordination of a community survey as part of the Eurocoord work package 14 new science work. The AMASE online survey will focus mainly on the barriers to accessing health care for migrant communities. The aim is to recruit migrants (defined as anyone living outside their country of birth for longer than 6 months) from populations at higher risk of HIV infection. Populations of interest include:

- African-born men and women
- Men and women who are injection drug users
- Men who have sex with men

Main Activities

A project coordinator was hired to chair the meetings of the aMASE Community Advisory Group meetings; coordinate the promotion of the survey and coordinate the discussions on the questionnaire. The survey was developed and tested in 2013. Possible promotional materials (flyers/leaflets, mini-cards, website, Facebook …) were discussed. Development of such materials will happen in 2014. The main activities of the survey are planned for 2014.

HIV-related entry, stay and residence restrictions, Together with the International AIDS Society (IAS), UNAIDS and GNP+, EATG held a satellite session on 'travel and residence restrictions based on HIV status' at the conference of the IAS in Kuala Lumpur, Malaysia. The session examined how the scientific community could contribute to evidence-informed and human rights-based migration policy. Speakers shared a personal experience of being deported after testing HIV positive while working abroad and looked at the vulnerabilities of migrant workers with their human rights and public health implications.

Efforts to overcome Australia's restrictions were discussed especially as it will host the 2014 International AIDS Conference in Melbourne.

Forced HIV testing in Greece

Following the decision of the Greek authorities on June 26 to re-introduce mandatory HIV testing for vulnerable groups under the Health Regulation n° GY/39A, EATG supported the Greek organisations in mobilizing pressure from the international community on Ministry of Health to ensure ethical and non-discriminatory HIV testing and sent a statement to the Minister of Health that while it is legitimate to prepare responses in the case of infectious disease epidemics, a decree used to detain vulnerable persons such as sex workers, drug users, undocumented migrants for isolation and coerced HIV testing is under no circumstances justifiable. The decree and its use represent an abuse of human rights and a public health risk. It fails to address the causes the epidemic, which lay in the impact of the economic crisis on individuals and insufficient prevention measures. Moreover, it serves to fuel the epidemic further by nourishing misconception, stigma and fear.

The European Commission reached out to the Minister and received assurance that the new law would comply with human rights. The decision has been suspended while a new regulation on communicable disease is being prepared.

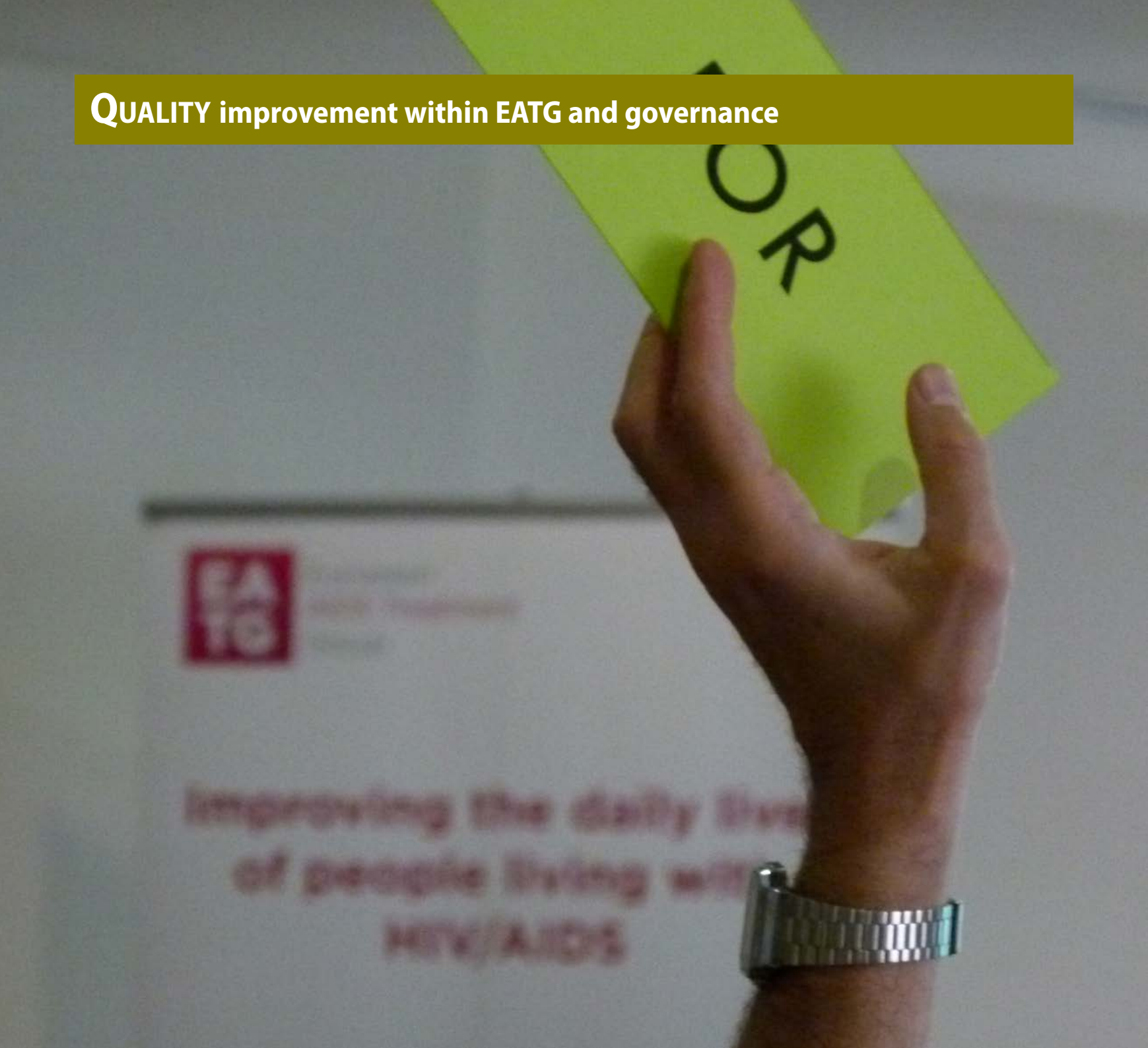
Criminalisation of HIV transmission

In October 2013, EATG published a position paper on prosecutions for HIV non-disclosure, exposure and/or transmission recommending that the criminal law should only be used in extremely rare and unusual cases where HIV is maliciously and intentionally transmitted.

EATG argues that while there may be a limited role for criminalising HIV transmission in terms of achieving jus-tice and/or punishment for wrongdoing in exceptional cases of malicious and deliberate HIV transmission that causes actual harm, the criminal law is too blunt and rigid a tool for dealing effectively with public health initiatives, controlling the spread of HIV, and deterring harm-risking conduct and is, therefore, detrimental to contemporary public health goals and human rights.

At the end of 2013 we had 67 members within the policy working group.

QUALITY improvement within EATG and governance



The ECAB review: "The impatient patient, from anger to activism"

In June 2012 ECAB launched the ECAB review project, a systematic review of the history, working models, relevance and perspectives of the European Community Advisory Board. The objective of the research/evaluation project was to review the role and functioning processes of the European Community Advisory Board and related CABs and professional groups in HIV/AIDS biomedical research with the objective to evaluate impact and to provide guidance and best practices for a possible model of interaction between patient organisations, industry, academia and regulators.

The review was performed by Tamás Bereczky. Preliminary results and recommendations were presented at the February 2013 ECAB and stakeholders meeting. A poster was produced and displayed at the EUPATI conference in Rome (19 April). Further promotion of the results was also done via a brochure that was distributed during ECAB meetings, Sitges, the IAS conference and the EACS conference in Brussels. http://www.eatg.org/gallery/168462/The%20impatient%20patient.pdf

EATG stakeholders meeting Brussels – February 4

EATG organised its 4th annual stakeholders (SH) meeting in Brussels on February 4. 30 participants joined us, including a wide range of stakeholders (NGOs, pharmaceutical companies, foundations …).

Topics covered during the meeting were the EATG 2013 work plan; preliminary results from the ECAB review; access to treatment in low prevalence countries; our training strategy and an open discussion on our collaboration with stakeholders.

EATG governance meeting
Brussels – May 23

During the May governance meeting the participants (board, chairs, staff and guests) discussed the following topics:

- Strategy development, communication about EATG and fundraising
  - o Some challenges like diversifying our funding have been turned into concrete action points.
- Achievements, outcomes and strategic priorities
  - o An essential starting point of the fundraising process would be to clarify the niche and how EATG makes a difference. This also entails a better reporting on where EATG contributed to scientific and political improvements for communities.
- Enhancing members involvement: DMAG proposal for new members
- The handbook revision

The discussion highlighted a number of action points for EATG (e.g.):

- improve evaluation of activities and reporting on achievements rather than activities;
- develop a business plan with 3-5 key goals and to break down expected outcomes into specific and realistic objectives;
- develop a long term financial plan that supports fundraising and the diversification of funds within the context of the business plan;
- increase diversity of the membership by actively recruiting new members to ensure variation in demographic representation and expertise (youth, migrants etc.)
- carry out an assessment of the specific training needs of members
- institutionalise capacity building through e-learning, website
- ….

The membership involvement project

This project focuses on how new and current members can be better integrated within the organisation and its activities.

The handbook/protocol review

Following previous agreements a small team within DMAG has started the handbook review process in collaboration with chairs, some members and staff. The new document will be a series of protocols that will clarify internal structures and processes.

The EATG Membership

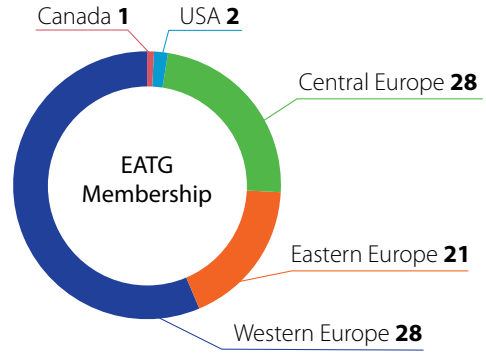
The EATG Membership

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.

Candidates that want to join EATG should have an interest in the topics covered by EATG. EATGs working language is English. Therefore candidates must have basic understanding of English. Preferably they should be involved in activities related to the EATG mission statement in their country of residence. Preference is given to people living with HIV/AIDS. Applications from candidate members are reviewed by the Development and Membership Advisory Group (DMAG).

In January 2013 we had 111 members. Some members left during the year, 18 new members joined, resulting in a total number of 119 members by the end of December, being active in the following 41 countries in Europe and Central Asia: Albania, Armenia, Austria, Belarus, Belgium, Bosnia & Herzegovina, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Georgia, Greece, Hungary, Ireland, Israel, Italy, Kosovo, Kyrgyzstan, Latvia, Lithuania, Macedonia, Netherlands, Poland, Portugal, Romania, Russian Federation, Serbia, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Tajikistan, Turkey, Ukraine, United Kingdom and Uzbekistan. We also have members from Canada and the United States.

Most members come from Western Europe[4], followed by Central Europe[5] and Eastern Europe[6].

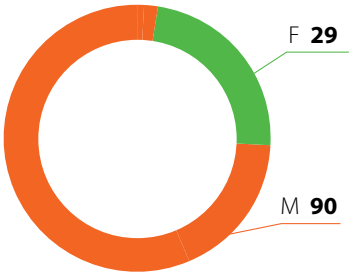


[4] *WHO definition of Western Europe (24 countries): Andorra, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, San Marino, Spain, Sweden, Switzerland, United Kingdom*

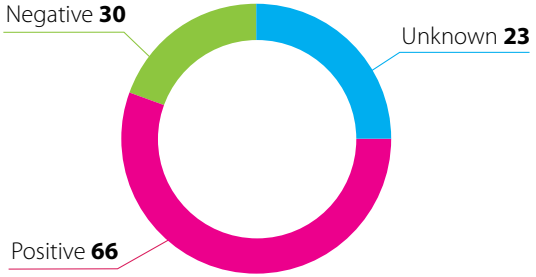
[5] *Central Europe (15 countries) : Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Hungary, the former Yugoslav Republic of Macedonia, Montenegro, Poland, Romania, Serbia, Slovakia, Slovenia, Turkey*

[6] *Eastern Europe (15 countries): Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, Russia, Tajikistan, Turkmenistan, Ukraine, Uzbekistan*

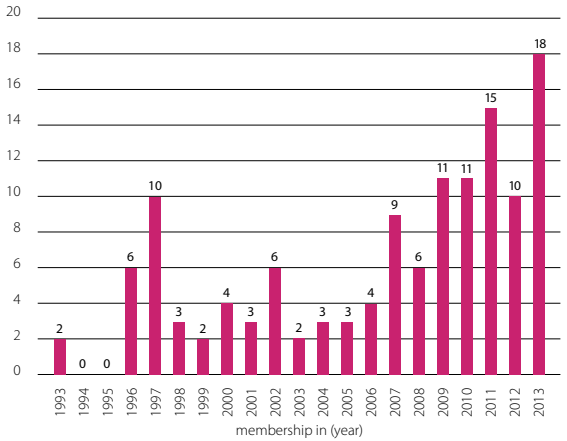
The increase in membership during the past years is reflected in the number of countries represented by our members. The increase also led to a more empowered representation from the different regions of Europe within the EATG. 24,37% of members are women. 75,63% are men.



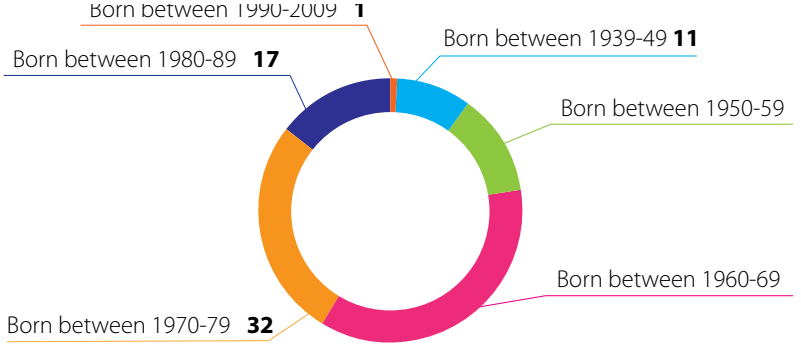
The HIV status of over 80% of our members is known (80,72%). At the end of December 2013 we had 30 HIV-negative members (25,21%), 66 HIV-positive members (55,46%) and 23 with an unknown status (19,33%).



The number of new members has considerably increased in the past few years. From our current membership most members joined the organisation in 2013 (n=18), followed by 2011 (n=15), 2009 and 2010 (n=11 for each year).



Most members are between 44 and 53 year old, being born between 1960 and 1969 (n=43), followed by 1970-1979 (n=32). 17 members are born between 1980 and 1989, 15 between 1950 and 1959 and 11 between 1939 and 1949. One person is born in 1993.



Finances

EATG Income 2013

		TOTAL	PERCENTAGE OF TOTAL INCOME
Donations			
	BOEHRINGER-INGELHEIM	76,000 €	7.13%
	GILEAD	221,500 €	20.77%
	MSD/MERCK	172,000 €	16.13%
	BMS	92,000 €	8.63%
	ABBVIE	49,418 €	4.63%
	JANSSEN	101,500 €	9.52%
	ViiV	169,082 €	15.86%
	TB ALLIANCE	1,485 €	0.14%
	COMMUNITY MEDIA TRUST	4,622 €	0.43%
	THERATECHNOLOGIES	16,000 €	1.50%
	MEMBERS	1,881 €	0.18%
Projects			
	ECRAN	8,453 €	0.79%
	Training Grant (SIDACTION)	25,948 €	2.43%
	HIV IN EUROPE	12,883 €	1.21%
	CHAARM	6,169 €	0.58%
	EUPATI	40,160 €	3.77%
	NEAT	23,370 €	2.19%
	ADVANCES	25,907 €	2.43%
	OTHER	2,735 €	0.26%
	Total	**1,051,112 €**	**98.58%**
Membership fees		**3,050 €**	**0.29%**
Interest		**419 €**	**0.04%**
Recoverable costs		**10,911 €**	**1.02%**
Other		**749 €**	**0.07%**
Total income 2013		**1,066,242 €**	**100.00%**

EATG Expenditure 2013

		Budget	TOTAL EXPENDITURE	% budget
Scientific Research	ECAB meetings, External Representation & Protocol Reviews	223,200 €	190,047 €	85.1%
	ECAB Review	9,104 €	9,104 €	100.0%
	NEAT Review	28,412 €	24,887 €	87.6%
	CHAARM Project	19,813 €	12,726 €	64.2%
	ECRAN Project	14,368 €	10,312 €	71.8%
	EUPATI Project	56,729 €	40,555 €	71.5%
	TOTAL	**351,625 €**	**287,631 €**	**81.8%**
Policy and Advocacy	Policy Working Group meetings, Policy Review, External Representation/other	78,100 €	72,776 €	93.2%
	aMASE Project	17,522 €	7,638 €	43.6%
	HIV in Europe Project	25,035 €	12,883 €	51.5%
	TOTAL	**120,657 €**	**93,297 €**	**77.3%**
HCV	Core Activity Budget and Sitges	127,410 €	88,727 €	69.6%
	Compassionate HCV Treatment use Initiative			
	TOTAL	**127,410 €**	**88,727 €**	**69.6%**
Other projects	Treatment as Prevention	7,100 €	11,146 €	157.0%
	COBASYS	0 €	2,737 €	n/a
	Eurocoord	1,420 €	1,071 €	75.4%
	Lisbon conference "Culture, sex and sexwork"	8,956 €	5,113 €	57.1%
	TOTAL	**17,476 €**	**20,067 €**	**114.8%**
Capacity Building	Training "Integrated approach in Treatment of HIV and related co-infections"	61,059 €	58,529 €	95.9%
	Training "Engaging and Empowering Young People for HIV/AIDS Treatment, Care & Prevention"	42,600 €	40,971 €	96.2%
	Training Academy	8,000 €	11,426 €	142.8%
	Training EATG Staff	4,970 €	3,626 €	73.0%
	COPE	17,040 €	17,166 €	100.7%
	Conference Support for staff	17,040 €	16,625 €	97.6%
	Representation & Capacity building for members	24,140 €	15,804 €	65.5%
	TOTAL	**174,849 €**	**164,148 €**	**93.9%**
Communication	Website content management, Publications, TB Online, IT Support	40,896 €	42,671 €	104.3%
	TOTAL	**40,896 €**	**42,671 €**	**104.3%**
Governance	Ombudspersons	1,420 €	0 €	0.0%
	GA	99,400 €	96,727 €	97.3%
	BOD	71,000 €	68,349 €	96.3%
	DMAG	17,040 €	10,572 €	62.0%
	Internal Auditors	20,235 €	15,788 €	78.0%
	Governance Meeting	5,680 €	4,305 €	75.8%
	Stakeholders Meeting	21,300 €	25,584 €	120.1%
	External Advisory Board	2,840 €	93 €	3.3%
	Fundraising	31,240 €	24,952 €	79.9%
	TOTAL	**270,155 €**	**246,371 €**	91.2%
Administration	Staff Salaries & office cost	110,810 €	136,250 €	123.0%
	Legal Advice	4,260 €	667 €	15.7%
	External Auditors	17,040 €	15,599 €	91.5%
	TOTAL	**132,110 €**	**152,517 €**	**115.4%**
OVERALL EXPENDITURE 2013		**1,235,178 €**	**1,095,428 €**	**88.7%**

Finances

EATG Budget 2014

		Budget
Scientific Research	ECAB meetings, External Representation & Protocol Reviews	212,910 €
	CHAARM Project	15,644 €
	ECRAN Project	15,572 €
	EUPATI Project	108,352 €
	TOTAL	**352,478 €**
Policy and Advocacy	Policy Working Group meetings, Policy Review, External Representation & other/other	75,228 €
	OPtest EC Project	17,788 €
	aMASE Project	19,968 €
	HIV in Europe Project	15,555 €
	TOTAL	**128,539 €**
HCV	Core Activity Budget, Sitges, Thematic access issues in HCV Treatment	106,349 €
	TOTAL	**106,349 €**
Other projects	Eurocoord	1,419 €
	TasP	7,097 €
	TOTAL	**8,516 €**
Capacity Building	EC Training Conference Project	124,840 €
	Training Academy	10,000 €
	BMS Training	33,410 €
	Sidaction 2013	3,773 €
	Training Staff	4,258 €
	COPE	19,433 €
	Conference Support for staff	23,997 €
	Representation & Capacity building for members	24,594 €
	TOTAL	**244,305 €**
Communication	Website content management, Publications, TB Online, IT Support	40,879 €
	TOTAL	**40,879 €**
Governance	Ombudspersons	1,419 €
	GA	98,761 €
	BOD	56,776 €
	DMAG	15,612 €
	Internal Auditors	5,677 €
	Governance Meeting	10,347 €
	Stakeholders Meeting	10,943 €
	External Advisory Board	3,548 €
	Fundraising	35,483 €
	TOTAL	**238,566 €**
Administration	Staff Salaries	133,548 €
	Legal Advice	4,258 €
	External Auditors	17,032 €
	TOTAL	**154,837 €**
OVERALL BUDGET 2014		**1,274,469 €**

Diversifying funding

During the past years we have seen that specific HIV funding has decreased importantly by pharmaceutical companies. This has been compensated by HCV and other funding but it shows how vulnerable our pharma related funding is, especially as fewer companies take bigger parts of the HIV and HCV market. The amount received from these market leaders does not fully compensate the loss from companies no longer supporting us by leaving the HIV market.

Important efforts are been made to diversify our funding. We are proud to have had a Training funded by Sidaction in 2013. We are also proud to announce that we have received an EC conference grant, as well as BMS Training and COPE funding for 2014.

Consultants have been contracted to support the work of staff members to apply to funds and organisations for project funding and we look forward to seeing results in the near future.

Reaching out

Website, Digest news and Visual Identity

In the last quarter of 2012 our new website was launched with the new visual identity of the organisation. EATG continues offering the service of the daily 'Global HIV News' for everyone interested in the latest developments around HIV/AIDS. The news feeds are updated daily and cover not only recent European developments but also stories from around the world.

The EATG website had an average of 368 visitors per day; the average number of hits was 14.765/ day. Most visits are short. 12.6% stay longer than 5 minutes. 7.4% even stay longer than 15 minutes.

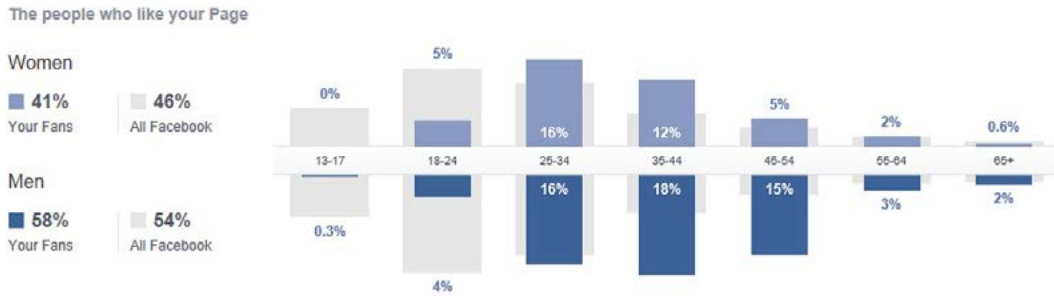
EATG also provides daily updates on tuberculosis on the www.tbonline.info website.

Social media

The EATG social media portfolio currently consists of a Facebook page, a twitter account and a YouTube channel where we inform our audience about EATG events, news and publications and interact with partner organisations and members.

We reached 324 people with our post on Facebook about the Call to Action for an EU strategy and Action plan on HIV/AIDS. In October and November we reached the highest number of people with the Facebook page reporting on the EACS conference (909 people on October 16) and the launch of the testing week (445 people on November 21).

EATG at IAS, the first announcement of the testing week in September, the launch of the STEP UP program, the publication of the ECAB review report "The Impatient Patient, from Anger to Activism" and the presentation of our new



Board of Directors also reached between 150 - 200 people each.

We can see an increase in "likes" on Facebook of about 17% from March till June. At the end of December we had all in all 344 total 'page likes' on Facebook. The testing week received 711 likes; EATG at IAS got 77 likes. The people that like our page are mostly men (58%).

The number of followers on twitter rose by 22% in the first 6 months of 2013. We were able to get 215 followers by the end of June. Nearly half of them were other organisations but also MEP's, journalists and people working for pharmaceutical companies. We uploaded one video of a training session on our YouTube channel and are soon going to start to put more material there.

The External News

Unfortunately our external news has been postponed several times so that we did not have any updated news for our stakeholders for the first 6 months. The first external newsletter appeared in June 2013. Other editions appeared in September and December. In 2014 we will be producing trimestral external newsletters.

Members' representation

In the beginning of 2013 we had 62 permanent representation positions performed by our members. During the first half of 2013 some evaluation was performed, resulting in a list of 42 representations by the end of June 2013. The identification of new/missing opportunities for representations will be performed.

EATG at conferences

EATG participated in the 2nd Conference on HIV infection among hidden groups in Lisbon (25-26 March, 2013); the International Liver Congress (EASL) in Amsterdam (24-28 April, 2013); and the Human Rights conference of the World Outgames in Antwerp (July 31st- August 2nd, 2013). We shared a booth with EACS at the IAS conference in Kuala Lumpur (30th June- 3rd July, 2013). EATG distributed the 2012 annual report, our leaflets, the ECAB review brochure and the 20th anniversary report. All publications were taken and people showed interested in the organisation. We also displayed the poster that was presented in Lisbon on the ECAB review.

EATG was part of a special session during the conference on travel restrictions and migration. Peter Wiessner gave a presentation on travel restrictions and the impact they have on the lives of PLHIV.

Acronyms and 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
CHAARM	Combined Highly Active Anti-Retroviral Microbicides (FP 7 project)
CHMP	Committee for Medicinal Products for Human Use
COPE	COntinuous Patient Education
Correlation	European Network Social Inclusion & Health
CSF	Civil Society Forum
CTAC	Canadian Treatment Action Council
ECAB	European Community Advisory Board
ECDC	European Centre for Disease prevention and Control
ECRAN	European Communication on Research Awareness Needs (FP 7 project)
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
EUPATI	European Patients' Academy on Therapeutic Innovation (FP 7 project)
EUROCOORD	Network of Excellence by several of the biggest HIV cohorts and collaborations within Europe - CASCADE, COHERE, EuroSIDA, and PENTA
EUROPRISE	European Vaccines and Microbicides Enterprise - Network of Excellence (FP 6 project)
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
NEAT	European AIDS Treatment Network (FP 7 project)
NeLP	Network of Low Prevalence countries
NNRTI	Non-Nucleoside Reverse Transcriptase Inhibitor
PCWP	Patient and Consumer Working Party
PDCO	Paediatric Committee
PLHIV	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

GOVERNANCE

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.

Anna Żakowicz, Poland (until September 14 2013)

Brian West, UK – Chair (and ECAB liaison) - Ferenc Bagyinszky, Hungary – vice-Chair (and DMAG liaison) - Tamás Bereczky, Hungary – Secretary (and PWG liaison) - Tomislav Vurusic - Treasurer - Olimbi Hoxhaj, Albania – Director (since September 14 2013)

The EATG External Advisory Board
Lella Cosmaro, Italy - Michel Kazatchkine, France - Jürgen Rockstroh, Germany - Matthew Weait, United Kingdom

The Development and Membership Advisory Group (DMAG)
The Development Membership Advisory Group DMAG is the internal group dealing with membership issues and internal working mechanisms.

DMAG chair: Jens Wilhelmsborg (until September) - José Rojas Lima e Silva

The Policy Working Group

Chairs
Peter Wiessner, Luis Mendaõ (since September 2013: Shona Schonning)

Steering Committee members
Aisuluu Bolotbaeva, Andrej Senih, Bryan Teixeira, Frank Amort, Giulio Maria Corbelli, Peter Wiessner

ECAB

Chairs
Paul Clift, Chris Cziria

Steering Committee members
Giulio Maria Corbelli, Evgenia Maron, Milena Stevanovic, Memory Sachikonye, Deniz Uyanik (until May 2013)

The staff members
Rubén Alonso, Project Assistant;
Giorgio Barbareschi, Scientific Adviser;
Koen Block, Executive Director;
Oleksandr Martynenko, Training & Communications Coordinator;
Marie McLeod, Financial Manager;
Ann Isabelle von Lingen, Policy Officer

Special thanks

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EATG members and staff

Many local, national and international NGOs

Partners and supporters

Among others: AIDS Action Europe • AIDSMAP.com • CHAARM steering committee • COBATEST • Collaboration of Observational HIV Epidemiological Research in Europe - COHERE • Correlation Network • Civil Society Forum on HIV • Civil Society Forum on Drugs • Drug interactions website • EACS 2013 • EACS guidelines • ECRAN • EMA - Patient & Consumer Working Party • EMA - Paediatric Committee (PedCo) • EMA management board • ENCePP Steering Committee • EPF • EPHA • Epposi • EUPATI • EuroCoord - Collaboration of Observational HIV Epidemiological Research in Europe • European Harm Reduction Network • European HIV Resistance Network • European Workshop on HIV & Hepatitis Treatment Strategies & Antiviral Drug Resistance • Forum for Collaborative HIV Research • Glasgow HIV 2014 (HIV 12) • Global Fund • GNP+ • HAART Oversight Committee (D:A:D study) • HIVERA • HIV in Europe • HPYP (Health Promotion for Young Prisoners) • International Planned Parenthood Federation – Europe • IQ-HIV • NEAT • PARTNER Study executive committee • Paediatric European Network for Treatment of AIDS (PENTA) • PROTECT External Advisory Board (EMA) • Quality Action • STOP TB Partnership • TB Europe Coalition (TBEC) • UNAIDS PCB • WHO Europe • WHO Civil Society Reference Group on HIV

Funders

AbbVie • Boehringer Ingelheim • Bristol-Myers Squibb • European Commission • Janssen • Gilead • Global Alliance • HIV in Europe • Merck • Roche • Sidaction • Theratechnologies • Viiv Healthcare


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