



European
AIDS Treatment
Group

2012 : A year of changes and celebration

Annual report summary
(January-December 2012)

Summary of achievements (January 2012 – December 2012)

2012 was a year of celebration and changes. EATG was founded in 1992 and legally registered on the 23th of February 1992 as a non-profit organization. In 2012 we celebrated our 20th anniversary, back in Berlin where it all began. For the 20 years anniversary a book has been created showing the history of treatment activism, the EATG history and the role of our members in the achievements of the past years.

EATG is proud and honoured for receiving a Red Award for the work that has been done in the past 20 years on HIV, treatment and access at the Reminders Night event in Berlin on September 22.

Improve AIDS policy at EU/international level

The Policy Working Group (PWG) currently has 63 members from 33 countries, providing input through their membership in the PWG, as well as external bodies like 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 co-chairs of the group were Raminta Stuikyte and Peter Wiessner. Luis Mendao replaced Raminta after the GA.

After the final **Correlation Network II** meeting in Ljubljana, the policy recommendations that were created by EATG for **4 vulnerable groups** (injecting drug users (IDU), sex workers, men who have sex with men (MSM) and migrant populations) were presented at the HIV in Europe conference (April 19-20) in Copenhagen (<http://www.correlation-net.org/>). At the same conference Frank Amort, EATG member from Austria, also presented a poster with results from a survey on “Expectations and Perceptions of European Men who have Sex with Men on Voluntary Testing and Counselling”.

In May 2012, a **Policy Dialogue Meeting** took place in connection to training and consultation of local community representatives (St Petersburg, Russia, May 25, 2012). The main topic of the meeting was “**Community Role in ensuring universal and uninterrupted access to HIV treatment in Russia**”. The agenda was prepared by the local communities (ITPC-EECA, the Community of People Living with HIV, Moscow) in collaboration with EATG. Representatives from the WHO, UNAIDS and UNDP took part in the meeting; however none of the invited representatives of the Russian authorities attended. The meeting highlighted the need to foster dialogue with state authorities, to strengthen the capacities of community groups in different regions to engage in discussions around the development of protocols and procurement laws; the establishment of a patient register; monitoring stock-outs and the quality of treatment.

EATG continued serving as Advocacy Secretariat of the **HIV in Europe initiative**¹: 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 PWG started the development of two **position papers**: one on access and innovation and a second one on criminalisation.

On 20 September 2012, together with Deutsche AIDS-Hilfe (DAH) and the International Planned Parenthood Federation, the European AIDS Treatment Group held an **HIV criminalisation seminar** in Berlin, Germany. The event, supported in part by the HIV in Europe initiative, brought together civil society advocates from across Europe and central Asia, with human rights experts, prosecutors, clinicians, parliamentarians and representatives of UNAIDS and UNDP. Participants shared knowledge and explored ways of securing an effective response to the overly-broad use of the criminal law as it relates to HIV non-disclosure, potential or perceived exposure and non-malicious transmission across Europe and central Asia. A meeting report is available on EATG's website.

EATG is also co-chair of 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. Two meetings took place during the year: in June and December 2012. In the session on “access”, EATG reported on the meeting in St Petersburg, updated participants about its work around treatment interruptions, the situation in low prevalence countries and the position paper on Access that is being developed. Edwin Bernard, an EATG member, was invited to discuss issues around the criminalisation of HIV transmission and exposure and initiatives to address it. A poster was prepared for and presented during the HIV in Europe conference. Two moments were reserved to provide clarification to people that required additional information. The poster showed the context of the Policy Recommendations that were drafted within the framework of the Correlation Network. It also showed all 10 recommendations that were created. Additionally some printed material was available for participants:

- A folder from the Correlation Network with more information about the network and its activities
- A brochure with the summary of the recommendations
- The complete report of our workpackage
- Agenda
- Report

¹ In line with objective 1.1.4: EATG continues to hold the political secretariat of the HIV in Europe initiative

Summary of achievements (January 2012 – December 2012)

During each session participants to the conference asked for more information. Another poster that was supported by EATG was a small research performed by Frank Amort: “Expectations and Perceptions of European Men who have Sex with Men on Voluntary Testing and Counselling”.

Promote treatment preparedness and build capacity

Capacity building is a continuous process. As part of this process EATG organises training sessions on an ad-hoc project-based basis. EATG has a dedicated pool of trainers who, in collaboration with the training coordinator, organize several training activities per year. The objective is to develop treatment knowledge of local HIV communities as well as their skills to advocate for access to uninterrupted and affordable HIV/AIDS treatment in their countries. Capacity building activities are designed in the framework “train the trainers,” whereby participants become trainers in their countries and support EATG in strengthening the capacity of the communities locally.

As mentioned, EATG organised in collaboration with local partners **training and consultation in Saint-Petersburg** in May on the “Role of Community Organisations in Providing Universal and

Uninterrupted Access to HIV Treatment in Russia”. The event included: training for activists, a strategic planning meeting and a policy dialogue with international organisations to discuss the advocacy strategy that was developed by community groups.

In November, EATG performed **training in Almaty, Kazakhstan** on HIV/AIDS treatment literacy and treatment advocacy, in collaboration with AIDS Foundation East West. Targeting PL-HIV, vulnerable groups, their supporters, national organizations and health entities, the programme was drafted to enable participants to apply acquired skills on HIV/AIDS treatment literacy and advocacy on both regional and national levels and to further promote the adherence to HIV treatment and care support across Central Asia. A total of 11 thematic presentations were delivered during the training. Those were complimented by two group workshops that were moderated by the trainers, with plenary de-briefings and group discussions following each of the workshops.

The **Continuous Patient Education Project (COPE)** is a mechanism for funding the adaptation, translation, production and dissemination of HIV/AIDS treatment materials. In 2012 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 5 publications in 3 languages: Lithuanian, Latvian and Bulgarian.

Summary of achievements (January 2012 – December 2012)

Improve clinical research and drug development and access to prevention, treatment and care in the WHO euro region

ECAB is the working group of EATG working towards improving clinical research and drug development and access to prevention, treatment and care in the WHO EURO region. 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. By the end of December ECAB counted 70 members from EATG within its membership and 31 external guests. Via the EATG membership 41 countries are represented including 20 countries from Central and Eastern Europe.

From January to December 2012, 4 ECAB meetings focusing on HIV/AIDS took place:

- January: meeting with Abbott and a training session on HIV and the brain.
- March: meeting with ViiV Healthcare and Gilead and a presentation by Dr. Dana Rosenfeld on HIV & ageing, as well as a feedback session from Svilen Konov on 'Patient reporting

of medicines-related adverse reactions'.

- June: meeting with Bristol-Myers Squibb (BMS) and Merck, Sharp & Dohme (MSD).
- October: meeting with Gilead and Janssen and half day training on HIV-2 scientific and medical issues.

Following the discussions on the increasing need for actions in the **HCV co-infection** field, a Hepatitis Consultant was hired. The consultant supported EATG in the drafting of its hepatitis work plan 2012 – 2015.

ECAB also organised 2 thematic ECABs:

- The May ECAB: focused on HCV drug development with Abbott and Merck, Sharp & Dohme (MSD). A thematic training took place focused on HCV biosimilars in order to get a clearer picture on the scientific and legal background linked to biologics' substitution.
- The December ECAB meeting (Dec 7-9, 2012) was the second HCV thematic meeting of 2012. ECAB met with Janssen, Boehringer Ingelheim, Bristol-Myers Squibb (BMS) and Achillion.

On October 5-7, ECAB hosted Sitges V, the fifth in a series of multi-stakeholder meetings

Summary of achievements (January 2012 – December 2012)

on development of, and access to experimental therapies for hepatitis C virus (HCV). Sitges V was focused on facilitating clinical trials of, and access to interferon-free regimens for people co-infected with HIV and Hepatitis C (and other priority populations, such as pre-and post-transplant).

An important expertise of ECAB is to review clinical trial protocols and informed consent sheets from the PLHIV Community's perspective and needs. From January to December 2012, ECAB reviewed 9 clinical trial protocols and 1 informed consent form from different pharmaceutical companies and research institutions.

ECAB was involved in different projects: EUROCOORD, ECRAN, EUPATI, NEAT, CHAARM. EUROPRISE did end in 2012.

Visibility

Press releases were launched, position papers drafted, statements supported and meetings organized. In collaboration with HIV Europe EATG hosted the European Community booth at the Washington conference and organized a series of events and seminars at the booth. EATG members were involved in the organization of sessions at the conference and acted as co-chairs of different sessions such as the bridging session on Friday 27 on "Balance between Justice System and Provision of Services". In

September EATG launched its new visual identity with a new logo.

EATG was also present at the HIV 11 conference (the 11th International Congress on Drug Therapy in HIV infection Glasgow 2012) with a booth, the organization of a community session and a community feedback dinner). The community session was co-organised with UKCAB, highlighting a community focus on treatment.





EATG 20 years anniversary

EATG was founded in 1992 and legally registered on the 23th of February 1992 as a non-profit organization. In 2012 we celebrated our 20th anniversary, back in Berlin where it all began. Prior to our General Assembly EATG organized a seminar on Criminalisation followed by the celebration in the evening of our anniversary. During the celebration founding members were honoured for the pioneering role they had played in setting up an organization that focused on treatment within Europe in the early years of HIV treatment (even before combination therapy). Tribute was also given to previous board members. There was also a commemoration of founding members that have passed away.

For the 20 years anniversary a book has been created showing the history of treatment activism, the EATG history and the role of our members in the achievements of the past years.

On September 22, the day after our 20 years celebration the members and staff of EATG were honoured by receiving the **Reminders Day Award** (ReD-Award) for the 20 years of work that the organization has been doing on HIV treatment access and innovation. Since 2001 the Red Award is given during the 'Reminder Day AIDS Gala' to recognize the outstanding work that a person or organisation has performed in the fight against HIV and AIDS. In 2012 both Gery Kreszler, the initiator of the Life Ball in Wien and the European AIDS Treatment Group received a Red Award for their achievements and their role in the fight against HIV/AIDS.

The award was given to Koen Block, Executive Director of EATG, by Sir Nicolas Partridge. Mathias Wienold, an EATG member from Berlin and co-founder of the organization and Anna Żakowicz, current board member of the organization were also present when the award was given.

2012 Income

The total income in 2012 was projected at around 1.112.000 EUR. Out of these, 1.034.480 EUR were received by the end of 2012. A high

percentage of funding was received very late in the year which is why – during the year – expenses needed to be monitored very carefully.

	AMOUNT IN EURO	PERCENTAGE OF TOTAL INCOME
Donations		
Boehringer-Ingelheim GmbH	47,000	4.54%
GILEAD	178,194	17.23%
ACHILLION	15,871	1.53%
MSD	150,000	14.50%
BMS	9,347	0.90%
ROCHE	29,000	2.80%
ABBOTT	140,795	13.61%
JANSSEN	92,000	8.89%
ViiV	170,918	16.52%
IPPF	7,904	0.76%
MEMBERS	1,315	0.13%
Other	220	0.02%
Projects		
COPE (BMS)	16,076	1.55%
ECRAN	3,341	0.32%
Training Grant (BMS)	30,035	2.90%
Training Grant (Sidaction)	9,999	0.97%
LEVIS	44,038	4.26%
CHAARM	4,914	0.48%
EUPATI	30,745	2.97%
NEAT	13,916	1.35%
ADVANCES	9,515	0.92%
Other	5,693	0.55%
Total	1,010,835	97.71%
Membership fees	2,850	0.28%
Interest	852	0.08%
Recoverable costs	17,196	1.66%
Other	2,747	0.27%
Total income 2012	1,034,480	100.00%

2012 Expenditure

Expenditure in 2012 totals 1076382 EUR, i.e. 89% of the projected budget for the year.

The planned budget was used within the limits of individual budget lines.

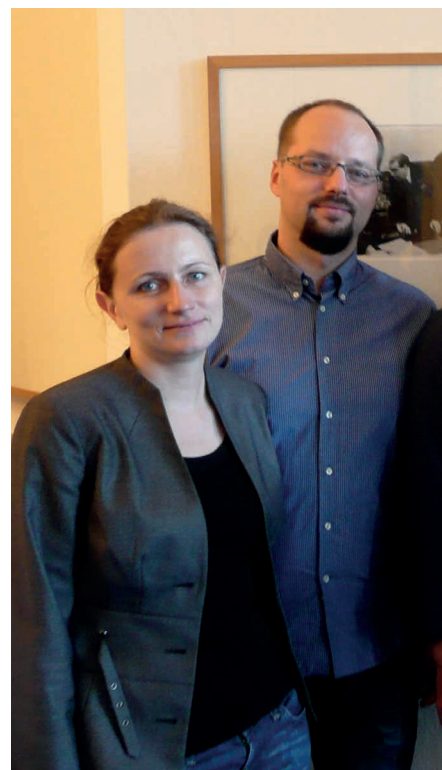
EATG EXPENDITURE 2012		Total Expenditure 2012 (euros)
Scientific Research	HIV ECABs, ECAB Review, representation & other	154.663
	HCV ECABs, Sitges, Hepatitis Portfolio	118.861
	NEAT Project	17.368
	CHAARM Project	10.228
	Europeprise Project	10.277
	ECRAN Project	4.226
	EUPATI Project	34.410
	SUBTOTAL	350.033
Policy and Advocacy	Policy Working Group meetings, representation & other	87.885
	Correlation Network II Project	2.580
	Criminalisation Seminar	41.846
	HIV in Europe Project	17.069
	SUBTOTAL	149.379
Capacity Building	EATG Trainings	59.742
	Training Staff	969
	Training Workshop and Policy Dialogue meeting Project	44.038
	COPE	21.746
	Conference Support & other	38.563
	SUBTOTAL	165.058
Communications	Website, publications & similar	67.764
	SUBTOTAL	67.764
Governance	General Assembly incl. 20 yr anniversary events	102.341
	BOD	41.314
	DMAG	12.681
	Internal Auditors	3.750
	Governance Meeting	17.617
	Stakeholders Meeting	5.547
	Fundraising	15.574
	SUBTOTAL	198.824
Administration	Staff Salaries & office costs	128.251
	External Auditors	17.074
	SUBTOTAL	145.325
GRAND TOTAL 2012		1.076.382

EATG Social Accounting

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. Therefore it is very important for us to show and value the work and time dedicated to the organisation by our members.

In 2011 EATG started this process of collecting volunteer hours. We converted the volunteer work into figures by calculating what each volunteer hour would have cost EATG if we would have had to employ staff to do the work instead.

In 2012 the total number of volunteer hours by EATG members that registered was 9071; the monetary value of which is 307473 . EATG is extremely proud of this achievement and thanks all the participating members for this fantastic result.





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 23, 2012:

Ferenc Bagyinszky, Hungary - Chair

Stefan Stojanovik, Macedonia - Treasurer (replaced by Tomislav Vurusic who was co-opted in May 2012)

Brian West, UK - Secretary

The Board of Directors

EATG BOD from September 23 until December 31, 2012:

Brian West, UK - Chair

Ferenc Bagyinszky, Hungary - vice-Chair

Tamás Bereczky, Hungary - Secretary

Tomislav Vurusic - Treasurer

Anna Żakowicz, Poland - Director

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.

EATG stakeholders meeting - Brussels - June 18

EATG organised its annual stakeholders (SH) meeting in Brussels on June 18. This was the 3rd SH organised by the organisation. We had 30 participants including a wide range of stakeholders (NGOs, pharma, foundations ...).

Topics covered during the meeting were the achievements of 2011, the work EATG plans to perform on hepatitis (as co-infection), past and future trainings and our Policy Dialogue Meetings.

Quite some participants highlighted the rather unique role EATG has been playing (and still has) on pushing the scientific research agenda forward.



European
AIDS Treatment
Group

The EATG is a nongovernmental organisation that defends the interests of people living with HIV by focusing on treatment activism and treatment advocacy. We promote legislative changes that will help increase access to HIV treatment and care, and we monitor the development, testing and approval of new HIV treatments with respect to the needs and rights of people living with HIV.

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

EATG office:
Place Raymond Blyckaerts 13,
B-1050 Brussels,
Belgium

www.eatg.org

