

25 Anniversary Publication



European
AIDS Treatment
Group

25 years of HIV treatment activism



European
AIDS Treatment
Group

Activism for change:
25 years of patient-led European HIV advocacy

Ian Hodgson prepared this publication, with the generous assistance of Tamás Bereczky, Koen Block, and Deniz Uyanik. Particular thanks go to EATG members contributing to this report through an online survey, and others who gave their time for individual interviews. We are especially grateful to those who consented to being quoted in the text.

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Foreword



This year EATG celebrates its 25th anniversary. It sounds long time (one quarter of a century). The history of the organisation begins at the first AIDS & Medication meeting in 1991, with official registration some months later in 1992.

I have the privilege of being part of the organisation during an important period, with my EATG 'career' starting in the late 1990s when I joined as a member, and becoming Executive Director in 2009.

After the Vancouver conference in 1996 access to treatment was a major topic for patients in Belgium. It was the same in many other countries, as shown recently in the movie '120 battements par minute' (2017). Protease inhibitors had proved their efficacy, and patients were desperately in need of access. Unfortunately, criteria were strict in the early years and reimbursement wasn't provided quickly. Locally, we decided to set up a 'Medication Working Group' to advocate for access and reimbursement. History has shown that these activities were not without success.

Joining EATG helped our local group learn more about the development

of treatments. We received support in writing letters to advocate for the approval of new drugs, and for information about drug trials and studies in Belgium. We advocated for some of the trials, thus helping patients access newer drugs. Many stories like this are available within our membership, which has grown within the last few years. We hear stories of success, and stories of continuing challenges and barriers.

EATG has been at the forefront of many developments, such as the search for improved hepatitis C treatments, and the development of a cure. We played a major role in advocacy for PrEP research and access. We have been involved in vaccines, microbicides trials, and strongly support a diversified approach to prevention.

EATG has also been very determined in the inclusion of key affected and vulnerable populations, such as migrants, injecting drug users, sex workers, MSM, and women. Even if diversity was not always strongly reflected in our membership, EATG has always defended equality in access to treatment, care, prevention, services, and testing. EATG today is no longer the organisation it was at the beginning, though we still defend the same values and principles as in the early years. We have achieved a lot in these 25 years but it sometimes seems like the battle is only just beginning. The gap between east and west seems to be growing, and rights and standards of care seem to be diminishing in many countries

because of economic restrictions, because of politics, because of austerity.

It would be nice to say that, after 25 years, we have achieved our goals and changed the world. I truly believe we have changed certain things, but there is still a long way to go. Many question HIV exceptionalism, including myself. Better integration of HIV with existing structures and settings is certainly needed, but we can't ignore the fact that extra efforts are needed to remove barriers to services for key populations affected by HIV. We need more efforts in defending the rights of vulnerable groups and create better support, understanding, solidarity, and to fight stigma and discrimination. This includes the HIV self-stigma we often see.

So, I'd like to thank everyone who has been active in our endeavours, for their contribution to making the world a bit better for PLHIV and those affected by HIV. I call all those present now for continued support in our future work and hopefully, together, we will see real change in the coming years when people living with HIV receive the best standard of care, treatment, access to services, and live lives that are not only increasing in years, but in quality of life.

I hope you enjoy reading this report, and thank you for your continued support and interest.

Koen Block
Executive Director



With the help of EATG, treatment and care are better,
and testing options and prevention have improved.

Respondent, Membership Survey 2017



EATG remains the only European-wide HIV activist network
Henning Mikkelsen, formerly-UNAIDS



1. What is EATG?

In 2017, EATG remains one of the only member-led organisations of its kind in the European region, and as such is able to give a face to HIV in Europe. As an organisation focusing on HIV, not only learning from the past but also evolving, EATG's patient community voice is a feature that mustn't be taken for granted, and a feature often lacking from other areas of health, where affected people are often unable to make meaningful contribution.

EATG is essentially a volunteer, grassroots organisation, providing a level of vibrancy often characteristic of national organisations but at a European level. It is made up of a tapestry of members from a wide range of backgrounds and levels of experience - some at the very beginning of their careers in the HIV sector and others at a highly advanced level with a significant depth of knowledge in science, training, and policy. With its melting pot of patient representation, mixed skillset, hard advocacy, and institutional memory, EATG is not only unique in the European-level HIV sector, but also within the context of organisations working with other diseases which, though seeking similar goals to EATG, lack the powerful ingredients that EATG offers. EATG is, essentially, a mass organisation of activists that mentors and trains the patient community, aiming for 'wins' at the regional and local level.

How is EATG unique?

First of all, EATG is one of the few European-level HIV patient-led organisations, providing a direct conduit for members to access European level resources and policy makers, particularly in the European Commission. It is led by people living with HIV, and unites members from one side of the European region to the other; from its most Western point, Ireland and the UK, to its most eastern, Tajikistan – a distance of 5600 km. Its individual style of membership and patient voice creates the main difference with partner organisations such as AIDS Action Europe (AAE) that have a similar function. Though as a network of HIV organisations, rather than patients, AAE has a stronger focus on national level policies. With its mix of a Brussels secretariat working with individual members, EATG has the potential to provide a stovepipe to the highest level of European-level policy making.

Secondly, EATG is able to react rapidly, generating member-led responses to significant events across the European HIV sector; something that would be difficult for umbrella organisations to achieve in such short a time. With its activist approach, EATG is also able to speak forthrightly in policy forums - illustrated by 'hard advocacy' to address issues in the prevention space, such as pre-exposure prophylaxis (PrEP). EATG is one of the few organisations able

to cultivate this form of activism in regional forums. Moreover it contains a mix of economic perspectives, some members politically left, others politically right, but all focused on the interests of the patient.

EATG therefore has the whole caboodle. It covers the spectrum of what a person living with HIV (PLHIV) needs for activism, and acts for those who can't fight for themselves by providing support, training and parliamentary advocacy. This is achieved with only a small number of permanent staff and a relatively small annual budget of less than € 2m as of 2017. For new members, it can take a while to appreciate fully the range of services EATG offers and all that it achieves.

The EATG strategy developed in 2016, 'Intensifying our HIV activism in Europe', includes a primary issue facing the HIV community, that of HIV stigma. EATG responds when possible to issues facing PLHIV in the European region, for example in 2016, in support to Czech colleagues, EATG and partners reached out to the Prague Public Health Authority, the European Commission, ECDC, WHO, and UNAIDS to raise concerns with Czech authorities about the police investigation into the sex lives of 30 men living with HIV on the sole grounds that these men have been diagnosed with a sexually transmitted infection from public health and fundamental rights perspectives.¹

We have good experience in working with patients, and empowerment – it stands out from other disease areas. We have the experience of how to make patients important – and also help them be confident and represent [their needs]. If we look at groups who are disadvantaged, they have to interact with people like politicians and researchers. We need to help how to represent [our] knowledge in more disadvantaged areas of Europe.

Kristjan Jachnowitsch, Germany



Voice of the community and community representation

As a membership-led organisation, EATG is in a strong position to represent its community and to be a strong voice for its members. EATG is ideally placed to speak on behalf of the HIV response and civil society in Europe, collectively a powerful advocacy tool.

How much does EATG speak on behalf of the patient community? A key example of representation is EATG's European Community Advisory Board (ECAB), but of course there are other forums in which the patient community's voice is facilitated, for example at conferences, European level meetings, and a large number of steering and advisory committees. EATG is also asked increasingly to be a community partner within EU projects. As the only patient-driven European HIV organisation EATG is in increasing demand, for example in the OptTEST project.² Initially, the involving the patient community was at risk of being tokenistic, but EATG now plays a more significant role – for example in vaccines work, and HIVACAR, a Spanish-led project exploring optimum treatments to find a cure for HIV.



As an EATG member, starting 2014, I am in a privileged position to access first-hand information, resources and knowledge accumulated by the global HIV movement. Using all of these I become more reliable in my daily activities as a social worker and HIV activist, especially when I interact with health care providers, pharma companies, and of course in relationships with my clients."

Ioan Petre, Romania

2. Where did we come from? A brief history of EATG - 1992-2012

Beginnings: how EATG began in 1992

The **birth of EATG** began in March 1991,³ when the Terrence Higgins Trust (THT) in London met with Deutsche AIDS-Hilfe (DAH) to discuss holding a seminar as part of European Commission-sponsored series. Since DAH was the only organisation with staff working specifically on treatment, THT asked DAH to organise a seminar on AIDS and medicine. This became the first AIDS & Medication meeting. The head of DAH's department of medicine and health policy, Matthias Wienold, after consulting with Nick Partridge (THT), Robin Gorna (European Commission), and two German activist friends, Andreas

Salmen and Jürgen Poppinger, decided on a specific focus: treatment activism. At the time, few people shared this particular interest.

About a dozen activists attended the inaugural AIDS & Medication meeting in May 1991 representing Germany, the UK, and three other European countries. They discussed what treatment activism – primarily an American phenomenon – might look like in a European setting. In the wake of recent difficulties over DDI (Didanosine), participants were excited about the prospect of joining forces as an advocacy grouping. Three areas for action were identified: access to treatment,

standards of ethical conduct, and treatment education and information. This led to the first European AIDS Treatment Agenda developed in time for the VII International AIDS Conference held in Florence, June 1991. The aim was to bring a European perspective on the treatment agenda, similar to the approach of ACT UP New York, and serve as a rallying cry for the European grouping and a basis for interactions with the pharmaceutical industry.

Other people gradually became involved in the nascent group, and participants began developing project ideas, including what

gestellt

9.-13. Februar 1992 fand in Berlin die Treffen der European AIDS Treatment Group (EATG) mit Teilnehmern aus 13 Europas sowie Vertretern der Mission und des Regionalbüros der WHO statt.

Die Vertreter von AIDS-Hilfen und Selbsthilfegruppen trafen sich in Berlin, um Informationen auszutauschen und Perspektiven zur Lösung der Probleme bei der AIDS-auf europäischer Ebene zu ent-
wickeln.

Fassung der EATG haben The-
rapie- und Zulassungsverfahren
auf Ebene bislang nicht zu den
therapeutischen Fortschritts-
zum Ausmaß, dem Charak-
ter



Teilnehmer des EATG-Treffens in Berlin

Fotos: Reinhard Lorenz

became the European AIDS Trials Directory, ECAB, and a newsletter, European AIDS Treatment News (EATN). At the second AIDS & Medication meeting, convened in Berlin, February 1992, participants formally inaugurated themselves as the European AIDS Treatment Group, comprising 19 members from nine EC countries⁴ and Switzerland, as well as observers from the European Commission and WHO Europe. The proposed constitution was passed unanimously, limiting membership to individuals rather than organisations, and with an annual membership fee of 2 German marks (about € 1). A board was elected, consisting of Jonathan Grimshaw, Marc Regnard, and Matthias Wienold. Marc Regnard died shortly afterwards and was succeeded by Stephan Dressler. Matthias Wienold served as the first executive director, a post he held for three years. DAH agreed to host the secretariat and provide a home base.

In a membership appeal printed later that year in the EuroCASO Newsletter, Matthias explained why EATG had been founded, stating that, “To date there [has been] a failure of national drug research and approval systems to produce results of clinical and therapeutic value that match the scale, character and urgency of the HIV epidemic.” He went on to describe five priorities for EATG: changing the structure of research in Europe; improving access to information, medical services and

experimental drugs; and facilitating pan-European communication on treatment issues.

By 1993, the group had grown to 30 members from 14 countries almost entirely in Western and Northern Europe⁵. The AIDS & Medication meeting and the EATG General Assembly (GA) that followed were challenging due to language difficulties, hardball questions for company representatives, frustration with European regulators, and intense internal discussions. But the fact that treatment activists were finally collaborating across national borders and engaging with the industry and regulatory agencies showed that EATG was solidly established and making its voice heard. In 1994, EATG established a secretariat.

Evolution and growth – thematic highlights from 1994-2012

As an organisation

As an organisation, EATG has evolved and adapted over the years. By 1997 the organisation had grown to become a network of over **100 AIDS treatment activists** from 17 countries, and finally moved into its own office in Düsseldorf, which eased communication and disentangled its work from DAH. In 1998 the membership rolls were brought up to date, and the first membership handbook was developed, which over subsequent years would be revised a number of times. There was also the first major comprehensive organisational review that identified problems, obstacles, and opportunities. Passed by the GA, the recommendations included staff job descriptions, an ombudsperson,



new working groups, an electronic office and protocols for elections, GAs, budgeting and events.

In 2004 **EATG closed its Düsseldorf office and moved to Brussels** in order to interact with EU bodies more effectively, and highlights of its involvement in EU activities during the year included participating in a ministerial meeting organised by Ireland when it held the EU Presidency, and joining the new HIV/AIDS Think Tank set up by the Director General for Health and Consumer Protection (DG Sanco). This coincided EATG strengthening its links with **other advocacy organisations**, with harm reduction and drug users' groups from both the east and west of Europe, and with networks of people living with HIV such as the Central and Eastern European Harm Reduction Network (now the Eurasian Harm Reduction Network), Health Gap, the AIDS Treatment Activists Coalition, Gay Men's Health Crisis, and the Global Network of People Living with HIV/AIDS (GNP+).

The first EATG long term strategy, for 2006-2010, was developed in 2006, and partly as a result of this the organisation was streamlined into **just three working groups** in 2007: the Policy Working Group (PWG), ECAB, and the Development and Membership Working group (DMAG). There were also two task forces, Eastern States, and Capacity Building. This overall shape of EATG has remained in place for much of its existence. PWG in particular now covered a broad swathe of interests,



and by June 2007 it boasted 17 portfolios, including access to treatment and care, human rights, women, drug use, migrants, and the east of European. The increased level of policy activity led the organisation to hire a policy officer in 2007.

In July 2012, the European AIDS Treatment Group had 112 members from 40 countries. In addition to its recent connection with the EUPATI project, which addressed community involvement in scientific research and development, EATG decided to focus more on co-infections, especially hepatitis C.

Information sharing: Conferences

EATG has a long history of presentations and session facilitation at conferences that articulate EATG's mission and community experience. Some of the first included the 10th

international AIDS Conference in Yokohama, Japan, and the International Congress on Drug Therapy in HIV, Glasgow, where Matthias Wienold spoke at the closing plenary. EATG's collaboration with the Glasgow conference continues to this day. Shortly afterwards, EATG was represented at two other important conferences in 1995, the HIV Infection in Women Conference (Washington, DC), and the 6th International Conference on the Reduction of Drug Related Harm (Florence, Italy).

Other examples include facilitating sessions at the community forum on entry and travel regulations at the XVI International AIDS conference in Toronto, 2006, and a seminar at the Glasgow conference on the criminalisation of HIV transmission. This seminar paved the way for EATG's involvement the following

4 Austria, Denmark, Finland, France (3), Germany (6), Ireland, Italy, the Netherlands (2) and the United Kingdom (2).

5 Austria, Denmark, Finland, France, Germany, Hungary, Ireland, Italy, the Netherlands, Norway, Portugal, Spain, Switzerland and the United Kingdom.

year in a UNDP and UNAIDS consultation on the criminalisation of HIV transmission. Another core activity in 2006 was organising a conference, with a local NGO, in Lisbon on migrants' and ethnic minority rights to HIV services, attended by 230 community participants from throughout the European Region. This prepared community recommendations for the Portuguese presidency of the EU, which had chosen migration as its overarching theme. The recommendations also formed the basis for Migration and HIV/AIDS: Community Recommendations, prepared by the Civil Society Forum and published by EATG in 2008.

EATG also played a pivotal role in the first conference of the HIV in Europe Initiative, held in Brussels in November 2007 that brought together scientists, policy-makers and community members to explore and address the causes of late HIV diagnosis and barriers to testing. EATG assumed the role of advocacy secretariat for the initiative, a role it continues to play today.

In 2009, EATG organised a satellite community session in Glasgow, 'Can HAART prevent HIV transmission?' that produced a diverse mix of views on the Swiss Federal AIDS Commission's controversial assertion that it can eliminate it. The next year, it would also sponsor a satellite symposium on the same topic at the 6th International AIDS Society Conference on HIV Pathogenesis,

Treatment and Prevention in Rome. More recently EATG started organising satellite conferences on prevention and the CURE (called STEPS) that have been indicative for other presentations during the main conference. For the past several years EATG has been a constant member of the steering and scientific committees of EACS, HIV Glasgow, IAS and other conferences. In July 2012, European AIDS Treatment Group had 112 members from 40 countries. In addition to its recent connection with the EUPATI project, which addressed community involvement in scientific research and development, EATG decided to focus more on co-infections, especially hepatitis C.

Treatment advocacy and science: ECAB

A turning point in effective treatment was the historic 1996

independently of individual pharmaceutical companies, and accountable to EATG and the community. It would take a number of years to establish the ECAB model that would become dominant, but the core principle of independence of, and engagement with, the pharmaceutical industry continues to the present day.

From 1997 onwards there are a number of key achievements and milestones that illustrate the range of ECAB's work. The group developed an access template for all drugs of the companies working in the field, with details of the registration status, availability and re-imbusement of drugs in every European country. It developed a document on Standard of Care and also co-developed guidelines on treatment for countries facing stock out problems. ECAB also maintained close relationships with research groups, and formal



cooperation with the European Medicines Agency.

In addition, and consistent with EATG's broad mission, ECAB took a leading role in helping promote ECAB-like working models in difference European countries, such as UK-CAB, Spanish-CAB, and Ukrainian-CAB. This strengthened the empowerment of PLHIV in the field of treatment and research.

11th International AIDS Conference, held in Vancouver Canada. Here, the efficacy of combination therapy with protease inhibitors was first reported, and offered EATG a key focus for advocacy at the European level to ensure access to the new, potentially lifesaving treatments. EATG also discussed for the first time the idea of holding training sessions in southern Europe to educate new activists and increase community engagement.

In 1997 EATG organised its first community led European Community Advisory Board (ECAB) meeting. Other CABs were in existence, though as company-associated entities. Based on discussions at the 1994 AIDS & Medication meeting, EATG members decided not to represent individual constituencies, but to adopt instead an activist approach to clinical research and science based on a broader sense of community, embracing all affected groups throughout Europe. EATG's ECAB was therefore established



Capacity building - sharing and training

Sharing vital information with the community is a key role, and in 1995 EATG capitalised on the early growth of the Internet by making EATN available electronically. In addition, some 650 hard copies of each issue of EATN were distributed free of charge throughout Europe, and within a year there were 1000 subscribers, including 120 libraries. It was probably the most widely read treatment information newsletter in Europe. The EATN was largely supported during this period by pharma grants from on the condition of editorial independence – indeed, the firm was criticised openly and frequently by EATN, and this capacity to be objective in critiquing the pharmaceutical manufacturers has been an important characteristic of EATG.

Making publications available

in languages other than English became possible in 1997 when funding became available, and thanks to EU support, the EATN was realised in four languages in addition to English (French, Italian, Portuguese, and Spanish). In addition, in 1998 the organisation launched the Continuous Patient Education Project (CoPE) to translate educational materials, an initiative that came to fruition in 2000. In 1999 EATG also purchased the web domain www.eatg.org.

Since the early days of EATG, training has been a central part of EATG's work. In the summer of 1997, EATG arranged its first training course for treatment activists in southern Europe, in Barcelona, attended by around 100 delegates – primarily new treatment activists – from countries including Belgium, France, Greece, Italy, Portugal, Spain, Turkey, and the UK. These events



continued in 1999, and expanded eastwards for the first time by arranging its first training event for treatment activists in the central and eastern parts of Europe, forming part of the GNP+ conference in Warsaw.

EATG's training focus continued to expand, and in 2000 EATG started the **Trainers' Working Group**, organising training conferences in central and eastern Europe. These included a second training seminar for activists in Budapest, attended by 45 members of national NGOs. A third seminar followed in the same year attended by 70 NGO representatives in St. Petersburg. Both of these seminars targeted NGOs in the countries of the former Soviet Union, with participants coming from Belarus, Estonia,

Georgia, Latvia, Lithuania, the Russian Federation and Ukraine. As a related initiative, CoPE worked with local NGOs in the region to translate educational materials, starting with a leaflet on combination therapy. Between 2001 and 2006, CoPE would fund 27 translation projects, the majority focusing on central and eastern Europe.

In 2003, EATG clarified its **geographic focus** to include the entire WHO European Region, comprising 53 member states. This committed EATG explicitly to address treatment issues connected with the world's fastest growing epidemic, then in eastern Europe and central Asia – as it remains in 2017. This expanded focus led to EATG organising – in partnership with the All-Ukrainian Network of

People Living With HIV/AIDS – its fifth seminar for treatment activists in central and eastern Europe, this time focusing on access to treatment and harm reduction. Held in October 2003 in Kiev, the seminar was attended by 80 participants and featured an ECAB meeting dedicated to HIV issues in the region and enabled local advocates to meet with industry representatives to share concerns about access and pricing.

Training continued to be a focus and, in March 2008, EATG organised a **training workshop in Kiev** on national pharmaceutical procurement, supply, and reporting. In connection with the workshop, research was carried out in seven countries – Azerbaijan, Estonia, Kazakhstan, Kyrgyzstan, the

Republic of Moldova, the Russian Federation and Ukraine – looking at advocacy work on pharmaceutical procurement and supply issues that were limiting access to treatment in the region. EATG also renewed its emphasis on **training in central and eastern Europe**. Drawing on the findings of an extensive pan-European study on treatment literacy initiatives and training needs in eastern Europe, it acted to improve its existing projects, in part by creating a trainers' pool.

Two other examples provide insights into EATG's training focus. In 2010 ECAB **organised a meeting focusing on the clinical aspects of tuberculosis (TB)** and clinical research on TB/HIV co-infection, designed to serve as training for the European patient community and to help develop an advocacy agenda for them in the WHO European region. In June, it held a workshop on generic medicines in Kiev with the Eastern Europe and Central Asia CAB. ECAB began collaborating specifically with the Russian CAB during the year, advising them and sending representatives to their meetings.

Also in 2010, EATG organised **three training events on HIV treatment** literacy and advocacy in partnership with local community groups. The training, in Kiev, was held in conjunction with the All-Ukrainian Network of People Living with HIV, the training in Tallinn with

the Estonian Network of People Living with HIV and the training in Bucharest with Senz Positiv Romania.

Policy and treatment in Europe

The year 1997 was also the start of the **Lobbying Working Group** (LWG), later to become the Policy Working Group. With its formation, EATG was no longer just trying to stimulate treatment research; it also began to work politically for **treatment access**. The working group initiated formal contacts with several directorate generals (DGs) of the European Commission, and became central to EATG's work over the coming years. EATG started engaging more with both the European Commission and European Parliament, including an EATG-hosted meeting at the European Parliament on 24 May 2000 where EATG explained its vision for the role of HIV organisations and the need for prioritising the HIV on the EU health policy agenda. The group was renamed the **Policy Working Group** (PWG) in 2004. At the same time EATG was selected to represent civil society in the drafting panel of the Dublin Declaration⁶, and was successful in influencing the final statement. The PWG also contributed substantively to the Vilnius Declaration⁷ later in 2004, and around the same time EATG became more involved in the AIDS & Mobility project by developing an innovative health education model

for migrants and ethnic minorities.

EATG contributed to a growing number of policy forums from its early days. In 2003 EATG **engaged with several major UN bodies** for the first time. It also played a key role in developing the joint statement released by NGOs attending at the World Trade Organisation's Fifth Ministerial Conference in Cancun. EATG was involved in the bulk of formal motions and outside demonstrations during the meeting and participated in the high-level meeting devoted to the '3 by 5'⁸ Initiative, arranged in Geneva by the WHO, the Global Fund, and UNAIDS.

One of the most significant European policy-focused activities was birthed at a meeting with DG Sanco in May 2005, where EATG and AIDS Action Europe organised a consultation with NGOs on the EU's new approach to HIV in its member states and neighbouring countries. A chief outcome was the establishment of the **Civil Society Forum on HIV/AIDS** to complement the work of the HIV/AIDS Think Tank, which primarily consisted of government representatives. After initially having observer status EATG and AIDS Action Europe ultimately became co-chairs, a role in which they remain in 2017. EATG helped WHO Europe to initiate and oversee the drafting and publication of the first progress report on the Dublin Declaration published in 2008, assessing

⁷ "Vilnius Declaration" on Measures to Strengthen Responses to HIV/AIDS in the European Union and in Neighbouring Countries (2004). Available here: http://ec.europa.eu/health/ph_threats/com/aids/docs/ev_20040916_rd03_en.pdf

⁸ Launched by UNAIDS and WHO in 2003, and a global target to provide three million people living with HIV/AIDS in low- and middle-income countries with life-prolonging antiretroviral treatment (ART) by the end of 2005

how well European countries were delivering on actions they committed to in 2004, and providing a roadmap of what they needed to do next. EATG followed up in 2009 with an event in the European Parliament to demand that governments make good on their commitment to monitor their implementation of the Dublin Declaration.

In its role as the **advocacy secretariat of the HIV in Europe Initiative**, EATG organised in 2009 a roundtable in September with members of the European Parliament (MEPs) and other policy-makers, calling for a comprehensive EU strategy to promote early diagnosis, reduce barriers to testing and ensure earlier treatment and care. It led to the parliament passing a joint resolution on HIV in November with an unprecedented majority.

A standout activity for the group in 2011 was organising **policy dialogue**

meetings, starting with an event in Riga to follow up on discussions of the HIV situation in Latvia and Lithuania, particularly in light of the 2009 and 2010 UNODC country visit reports. The Hungarian Civil Liberties Union helped set up a second policy dialogue meeting in Budapest on the situation in low-prevalence countries, which was followed later in the year with a meeting in Belgrade to discuss how to address the problems in central and south-east Europe (low-prevalence countries) delineated in the Budapest Declaration, and a meeting in Bucharest. This meeting was the basis for the launch of the Network of Low Prevalence Countries of Central and South East Europe (NeLP) in 2011.

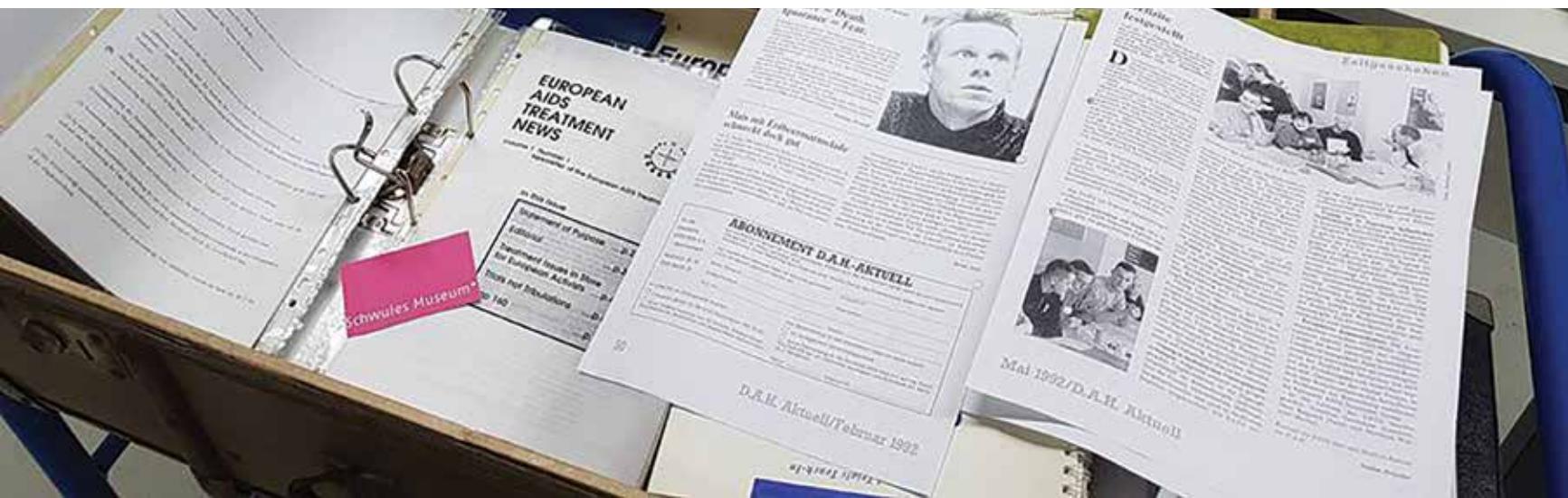
Another policy dialogue meeting, held earlier in Brussels, focused on HIV policy recommendations for the EU arising from the second and final phase of the Correlation Network project, where the PWG developed policy recommendations within

the framework of the Correlation II project (2009–2011), which tackled health inequalities in Europe.

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) in Berlin for the 20 years of work that the organization has been doing on HIV treatment access and innovation.

We need to find our space in this new world where most people in Western Europe have access to treatment and to focus on the unmet needs of PLHIV in the regions with lower access to treatment and prevention programmes, of key affected population and on quality of life.

**Mariana Vicente,
Belgium/ Portugal**



3. Synthesis – where are we now? 2013-2017

The Times They Are a-Changin'

Five years is a long time in the HIV sector. Since 2012, over 180,000 people have been newly infected with HIV in the WHO European region⁹. As in 2012, the epidemic in 2017 manifests differently in each of the European regions, along with health system effectiveness, availability of treatment, and civil society's response. Since 2012 there has been a significant transition in global health, from the Millennium Development Goals (running until 2015) that had specific reference to HIV in MDG 6a ('Have halted by 2015 and begun to reverse the spread of HIV/AIDS') and MDG 6b ('Achieve, by 2015, universal access to treatment for HIV/AIDS for all those who need it') to the *Sustainable Development Goals* (SDGs), where HIV has been folded into Goal 3: 'Ensure healthy lives and promote well-being for all at all ages', specifically, 'By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases.'¹⁰ This transition is consistent with the realigning of global health broadly, but presents a challenge for advocacy-focused organisations such as EATG to keep HIV firmly on national, regional, and global political and health agendas. In addition, sufficient attention is still required

to address the particular needs of key populations¹¹ – a focus for which EATG is ideally prepared.

EATG has also evolved since 2012. Membership has grown, with 112 from 40 countries in 2012 increasing to 182 members from 47 countries in 2017, become more regional (new members are increasingly coming from the east of Europe and central Asia), and representing progressive diversity (for example gender is now increasingly prominent as a topic focus). It comprises members working at multiple levels in their own countries, passionately working in HIV and making things better. There seems also to be a shift in the knowledge levels, with members having a broader range of prior experience, and this has driven the need for EATG to strategise capacity development approaches with the launch of the Training and Capacity Working Group (TCWG).

EATG has been acutely aware of the need for equal representation of affected groups at least since 2001, when internal data confirmed that, while keeping the cross-cutting membership priority on PLHIV, representation and diversity should be a key goal within the organisation. Major key populations affected by HIV were

underrepresented at that time, for example black and ethnic minority (BME) communities, migrants, injecting drug users (IDU), women, heterosexual men, parents of HIV-positive children, young people, and sex workers.

Since 2012, a stronger diversity has been evident in terms of geography, cultural diversity, age, and gender. Gender has been a topic for discussion in EATG since at least the early '00s. At the GA in 2001, members heard a report from the 'XX' group (sic). 'XX' was a subgroup of ECAB launched in 2000 to provide a dedicated focus on treatment issues affecting women. While the focus was specifically on treatment, this was one of the first examples of a gender-specific grouping in the organisation. Since that time, gender equity was sought in EATG recruitment processes and topics for discussion, and flagged as a membership issue, but it gained little purchase in the organisation as a central strategic priority focusing on women. Historically, the HIV movement in Europe and the Global North has been led and dominated by gay men. Indeed, being gay has been an essential part of this, and therefore it has been even more difficult for women, despite all efforts at inclusion, to

9 Source: ECDC 2017 statistics – <https://ecdc.europa.eu/en/hiv-infection-and-aids>

10 The UN Sustainable Development Goals - 17 Goals to Transform Our World. Online at: www.un.org/sustainabledevelopment/health/

11 International HIV/AIDS Alliance (2017). Community action is vital to achieve the Sustainable Development Goals. Online at: www.aidsalliance.org/news/954-community-action-essential-to-deliver-the-sdgs

12 See GA Report from 2013

present their interests. The group was dissolved some years later when EATG thought that gender issues were/would be well integrated in all activities done.

In some ways, 2013 can be seen as a turning point. At the GA that year a presentation by Evgenia Maron¹² highlighted specifically the social and psychological needs of women affected by HIV and, when taken globally, the equivalence of HIV prevalence between the genders. The following year, the membership

voted two women onto the Board of Directors, and a women's group was established which, unlike the first women's group in 2000, would have a remit beyond treatment issues and more on the special challenges faced by women living with HIV and on the need for gender sensitivity. The women's group still operates in 2017, and women continue to have an increasingly representative role in EATG, as epitomised in the appointment in 2016 of Jackie Morton as Chair of the Board of Directors. The risk of tokenism,

and the need to include non-male genders in core areas of decision-making and influence, is a challenge for all NGOs. EATG is not unique in this, and has taken steps to correct gender imbalance, but progress still needs to be made, especially – broadly – around the core principles of feminism. In 2017, a new group focusing on the needs of women living with HIV, 'EATG 4 Women', was launched after realising that specific focus was needed on scientific, training and policy issues.

The 'EATG 4 Women' portfolio was first introduced by Olimbi Hoxhaj during the time she was a member of the BoD (2013 – 2015) and has been supported by the members who followed her in the BoD, Sanja Belak and Jackie Morton (2015-2017). So far it has had two appointed coordinators, Aisuluu Bolotbaeva and Christina Antoniadi as well as two advisory committees.

Women living with HIV and affected by HIV have over time played a critical role in the HIV epidemic response. The results produced by their involvement have been unimaginable in some cases, such as the elimination of vertical transmission, an achievement for many countries today, and their leadership abilities have been proven quintessential in engaging entire communities in prevention and/or retention in care. EATG identified gaps in representation of specific women's needs within social and clinical science, as well as advocacy needs and lack in policy recommendations in recent years. That was the main driving force for creating this portfolio.



The 'EATG 4 Women' portfolio has managed in a very short time to identify gaps in representation, in clinical trials and both participation and leading roles in research, and has given a voice to women within EATG. It has contributed to the engagement of women from all geographic regions and backgrounds that are living with or affected by HIV. In the next steps, this portfolio will seek strategies to promote their leadership and seek meaningful participation to build capacities and networks in all EATG initiatives, where identifying gaps and engaging stakeholders to keep women at the centre of EATG's work.

PERSONAL STORY: JACKIE MORTON

As a trained nurse, I had worked my way through many structures of the UK's National Health Service, managing and leading many different professions such as GPs, hospital consultants, nurses, dentists, therapists, administrative staff, and allied health professionals. In 2009, my life took a dramatic change as I moved into the world of living with HIV. It was like a parallel universe from the world where I had lived for 56 years. I found men and women discriminated against for their sexuality or colour, stigmatised because of being diagnosed with a life-threatening disease, and neglected by political masters because of society's view of HIV. I felt driven to challenge these injustices at the highest possible level and, after retiring from the NHS in 2011, I dedicated my time as a volunteer to the HIV community.

In 2013, I met Brian West in Edinburgh during a conference run by HIV Scotland. I was thinking of broadening my experience but I wasn't sure in what way. Brian outlined the work of EATG, highlighting the need for more women activists in Europe and invited me to join. I felt there must be some way I could use my knowledge and skills to strengthen and raise the profile of women, and men, affected and infected with HIV across Europe, so I joined in 2014.

I didn't really know much about EATG. I read all I could but still felt inadequately prepared to become an activist alongside these very knowledgeable, educated, and pioneer activists, many of who had lived through the early years of the disease. What could I bring to this advanced group? I'd been assigned to ECAB and attended my first ECAB meeting in early 2014. Whilst I enjoyed learning more about the background of medicines and pipelines, it seemed a totally new language. I didn't know what a civil society forum was or how a membership organisation could influence parliamentarians across Europe. The issues seemed so vast, Europe so huge, the health systems so different to what I had been used to, and I grappled with what I could bring to the organisation.

At my second GA in 2015, I was approached to put my name forward for the board, and became a board member the following year. During my first year I struggled with the organisation's governance so, at the end of the year, I presented to the GA an option to review the current governance model. In 2016, the board members chose me as their chair and I found my forte. Leadership is what I do and I remain passionate to work with our members across Europe to focus on where we can be most effective. It has been a



pleasure to be EATG's chair in its 25th year of operation.

The world is changing for people living with HIV with its classification as a 'chronic' disease. But as the economy shrinks, and funding streams become more competitive, we still have many areas within Europe with high HIV prevalence. There is still much to do to ensure people across Europe have equitable access to treatment and prevention, to affordable medicines, to strengthen community advocacy and campaign for legal reform to protect their human rights.

HIV of course affects other groups, and EATG continues to strive for better representation from, for example, migrants, BME groups, sex workers, drug users, and other Key Affected Populations (KAP). EATG's expansion into the east of Europe and central Asia allows countries in the former Soviet Union to, according to one member, "Explain their plight to people outside of those places, helping with advocacy issues related to HIV, care, and treatment."

Since 2012, EATG has explored ways to make its governance more effective, in order to address the needs of the membership and to respond to external changes within the HIV sector which have a significant impact on its focus and modus operandi. These include challenges around funding, the increasing importance of prevention science (e.g. PrEP, and TasP), and rising levels of co-infections (for example hepatitis C). Responding to a core need at national and local level for education and support on HIV-related issues, especially in countries where there is need of local capacity building, has driven EATG to seek new methods of community engagement and empowerment.

Another key change since 2012 has been financial. Whilst EATG's budget requirement has expanded that time, sources of funding are becoming increasingly difficult to find, and this has forced EATG to explore additional, more creative ways to

support its work, including making a gradual shift towards more project-based activities. Communication remains a vital constituent, and in 2013 EATG appointed a Communications Coordinator to improve internal information sharing and transparency. Since then, communication within EATG has expanded through strategic use of Facebook, Twitter, and YouTube videos of capacity-building events, and webinar recordings.

A key document in 2016 was that outlining the new EATG strategy, 'Intensifying Our HIV Activism in Europe' (2016-2018). It includes seven strategic goals for EATG, and as a member-led product it articulates perhaps more than any other document the collective vision for EATG. The goals it sets broadly indicate that EATG aims to ensure its internal structures are fit for purpose, that communities have influence and that they are trained to become activists. Perhaps most significantly, it targets resources on access gaps and specific key

populations. The strategy helps EATG to adapt to a rapidly changing environment, and promotes a broad approach to HIV advocacy.

The new strategy is clear: 'To achieve the fastest possible access to state of the art medical products and devices, and diagnostic tests that prevent or treat HIV infection or improve the quality of life for people living with HIV, or at risk of HIV infection. In responding to HIV, EATG will also consider diseases frequently seen as co-infections in persons living with HIV, as well as other health issues that increase the risk of HIV infection'. Its core mission remains unchanged – particularly its strong focus on the rights of the patient – but the context within which the strategy is being operationalised is turbulent and changeable, especially as EATG engages with countries, often in the east of Europe, and central Asia, where the sector, and civil society, are very different from those in the west of Europe.





Younger members are joining from different countries that didn't seem well represented when I joined. I've seen people coming from very different fields and communities.

What fascinates me about EATG is the openness towards everything that is not mainstream. It is an open and liberal approach that sometimes you don't see in other, similar communities. EATG is more open and progressive. I'm drawing a parallel with the LBGTI community because there is an overlap (MSM is the largest group). This is a group who are best represented in EATG. We also now need to focus on other groups and communities who are marginalised and neglected, for example women.

Andrej Senih, Macedonia

Capacity building

The diversification of EATG, especially in terms of new members, is strengthening the breadth of EATG's work and offering new opportunities for capacity building for people who may live and work in countries where it is not easy to declare a positive HIV status (or to work in the HIV and HCV fields). There is also an increased need for translation to Russian and other regional languages. A future challenge for EATG will be to include those in local and regional initiatives where people have a working knowledge of HIV and policy but do not speak English (which was commonly required in the past).

Since 2012 there has been significant investment in EATG's commitment to structured training. EATG recognised the need to develop community activism at the local level and one example of this commitment is the EATG Training Academy Website to increase knowledge sharing and learning¹³. EATG developed and launched the Training Academy Website in 2016 to share information about all of its past, current and future training projects, and to provide access to all of the training materials that it had developed and facilitated. One member describes it this way: "I have grown professionally and personally through learning and sharing experiences from my peers in EATG."

[There's been] a huge change and scale up of these activities, which are good. Going back to my local organisation, we benefited by having one of our staff members attending STEP-UP. We used EATG for CoPE projects a couple of times to produce valuable materials in local language for PLHIV. What is new is the scale up and capacity building.

EATG Membership Survey, 2017

After an absence of several years EATG decided to set up a new working group for training. The launch of **the TCWG** in 2015 established a focused and strategic approach to training and education, with a significant financial investment in programmes and events. The strategic approach to training and knowledge sharing is perhaps best illustrated in two core projects, **STEP-UP**, which is based in the TCWG, and the **Ageing with HIV Project** that is a broader, cross-cutting EATG initiative.

STEP-UP is a five-module, year long training course developed by EATG. It has been designed to provide HIV education and personal development training to people who have an aspiration to become more active within the HIV community in

Europe and Central Asia¹⁴. Its aim is to help nurture the delivery of projects and activities across Europe, which will amplify the patient's voice and motivate policy makers and governments to ensure that HIV remains high on the agenda. The first intake of students was in 2013. Since that time around 20 advocates per year have completed the course. Evaluations undertaken so far indicate that it has a clear benefit for participants, and for one Irish participant from Ireland attending in 2017, "STEP-UP was the perfect way for me to increase my platform, to meet new people, to network and to increase my knowledge. It was just a win-win. To be able to be part of this has just been phenomenal." Further, more longitudinal, evaluations are planned. STEP-UP participants in 2017 originated from a wide range of countries in East, Central, and western Europe, and Central Asia, for example Malta, Poland, Ireland, Turkey, Belarus, Kazakhstan, and Uzbekistan. By increasing access to the east of Europe and central Asian (EECA) communities in particular, STEP-UP has enabled activists to strengthen advocacy competencies. It has also provided a basis for participants to go on to develop in-country projects, such as in Serbia in 2016, 'Case Management for better treatment efficiency'.



STEP-UP represents a significant achievement of EATG, in its reach and its potential impact. Whilst other components of EATG's work also represent key engagement with the European HIV sector, it is STEP-UP that is preparing the next generation of young activists. Activism is not new, of course, but bringing them together into one place for one course can galvanise and unify activism. One outcome has been increasing numbers of Checkpoints, which EATG (via STEP-UP) has contributed to. Community activists are now taking the battle to the national level. For one member: "The Training Academy is in my opinion the best EATG achievement. Implementing these training programs has helped EATG access funds which in return help the organisation to function daily, which is [acceptable] as long as we are delivering a good and useful 'service' to other HIV communities."

Maxime Journiac, France

The **Ageing with HIV Project** aims to address the challenges and the unmet needs of PLHIV within a lifecycle perspective. It has three phases: PLHIV aged 50+; Children and adolescents; and PLHIV for more than 10 years aged 18-40. For each phase, there are webinars, and a conference, bringing together the expertise, and the affected communities.

The ageing project has put ageing on the agenda across Europe, and has highlighted tensions and barriers in the care and support of the different age groups of people living with HIV – for example, the issue of condoms being too expensive for young people to buy in Romania or the complexities of 'polypharmacy' in PLHIV over 50 years of age.

Two conferences have been held so far, and what has perhaps been most significant is the involvement of the community in planning, preparing, and leading sessions during the events, alongside researchers, doctors, social workers, and psychologists.

As validation of this vital focus, at the AIDS2016 Conference held in Durban, South Africa, several sessions and satellites featured ageing with HIV, and the Ageing with HIV Project was mentioned and promoted several times.

KEY EXAMPLE: AGEING PROJECT CONFERENCE #1 APRIL 2016

According to a press release reporting from the first Ageing Project Conference in 2016, with the rate of PLHIV over the age of 50 years constantly increasing, and also the rate of new HIV diagnoses in this age group growing constantly, there is a stronger need to consider the biomedical and social, treatment-related, and political needs of this population systematically and in a targeted way. More than 90 participants gathered in Berlin, Germany for an intensive meeting of three and a half days.

Some of the key findings of the conference indicated that HIV treatment drugs are developed with primarily a younger population in mind; people with HIV aged 50 or older often have other diseases that may affect the way drugs work in their bodies. Specific studies on drug-drug interaction and on renal function in elderly people living with HIV are needed, as well as the parallel, holistic consideration of biological and social factors in the lives of PLHIV, the need to focus more on specific populations such as older women, migrants and trans* persons, and the need to educate health care providers about ageing; related issues, co-morbidities and polypharmacy. Maintaining a healthy lifestyle, including physical exercise and smoking cessation were also mentioned several times as key factors. Special attention is needed here as very few HIV tests are performed in the 50+ age group, and the rate of late presenters is alarmingly high¹⁵.



The increased emphasis on training in EATG has brought a new generation of advocates, supported by increasing numbers of targeted publications and resources that are being translated via the CoPE project.

Associated projects such as Continuous Patient Education (CoPE) and trainings towards KAP such as young people or migrants are designed to increase the capacity of affected people. M-CARE, which is aimed at migrant African communities, is particularly innovative, because it works to improve the capacity of key community leaders by further education, to support local members and to improve migrant community involvement in treatment related advocacy and activism. EATG, working in collaboration with European African Treatment Advocates Network (EATAN), has held two meetings in 2016 and 2017.



Training has also allowed EATG to strengthen its programming beyond 'just' HIV, by including co-infections, quality of life, ageing, living with stigma, and taking what has been learned and focusing on the entire lived experience of PLHIV. For one member: "Training has been a huge success. It needs to be. There's a generation of people like me who are aware [of] activities in the early days and are self-taught. There's a different generation now so we need to be doing that, and mentoring."

Brian West, Scotland



Another feature that has been expanding in EATG is the number of time-limited consultancy opportunities for members to lead on specific areas, allowing skill growth within the EATG and organisational learning. This includes report writing, increasing numbers of co-ordinators, and STEP-UP trainers. EATG clearly recognises the skillset of its members, which cements its aim to be a truly patient/person centred and led organisation.

Treatment advocacy: science, access, pricing, and affordability

EATG was created in 1992 to advocate for innovative research on treatment and maximise the availability of new treatments. When these drugs became available it soon became clear that many barriers existed which made the availability of treatment increasingly problematic. Aware of the needs of particular areas, EATG founded a new group in 2001, the **Access Working Group**, to focus on increasing access to treatment, with a strong focus on eastern Europe and low-income countries.

The situation now, in 2017, is markedly different, mainly as a result of EU expansion (eastwards after the fall of the Iron Curtain) having brought in countries with less effective, and less wealthy, health systems. Now that the efficacy of treatments has been established and access is rather ‘secured’ in most western European countries, the challenge for PLHIV in central and eastern Europe is mainly to gain access to treatments. EATG membership from these affected countries is increasing, and this has required EATG to shift emphasis – a process that has been gradual since the early ‘00s, but has been heightened since 2012. EATG developed in 2011 a position paper on access – which overlapped with issues around affordability, pricing and adopted a more activist approach to maximising access, rather than targeting demands

simply on government provision of treatment. Particular impact has been on the work of **ECAB**. Though the scientific work of ECAB is not finished, there is a quantifiable shift towards implementation, towards addressing issues such as drug availability, stigma, and outcomes, and asking questions such as: Where are governments not helping people? Where are drugs taking too long to work through the system? Where are drugs not available? Where are people being discriminated against? EATG’s expansion into the east of Europe has raised the prominence of these key challenges.

This shift has also highlighted the division across Europe. Where in the West complex discussions can be had about refining treatment regimes, expanding treatment as prevention, or clinical trials, for many countries in the east of Europe the major challenge is getting access to treatment in the first place. This difficulty illustrates the need to explore strategic interventions and targeted advocacy initiatives that match what is required locally, rather than decided centrally.

Since 2012 EATG has established an increasing focus on **affordability** as a joint policy and ECAB endeavour, with the formation of a members’ group, and introduction of the role of an Affordability Coordinator in 2015, and, in the related role of a Hepatitis

Coordinator in 2014. According to an EATG policy review released in 2015,¹⁶ “over the last five years significant organisational attention has been focused internally, undertaking discussions and processes to define EATG’s role in medicines’ affordability, including approaches to pricing policy and challenging barriers such as overly stringent intellectual property regimes.”

This focus has included strengthening members’ knowledge and agency on pricing policy and intellectual property issues. Pricing will continue to dominate discussions around affordability, especially in the current climate of austerity in many European countries, and the barriers to access, for example, through expensive viral hepatitis treatments. In 2016, the first of a planned series of webinars on affordability was offered, addressing issues such as the intellectual property international framework and some of the underused ways in which to ensure access to affordable state-of-the-art medicines for HIV, TB and HCV. It also included discussion on voluntary licensing – for example, through the Medicines Patent Pool, limits, improvements, and red lines for industry – and the also-underused possibilities of compulsory licensing, including those for prevention.

Pricing of medicines in particular has become a core issue in

improving access, and illustrates the paradigm shift from EATG's early years, where the provision of treatment was a primary aim, to the current where treatments are available but for countries, especially in the east of Europe, simply too expensive unless pricing is adjusted, or generics available. The capacity building of many activists in the east of Europe and central Asian, especially around pricing mechanisms, has been a priority, and one that EATG is still engaged with.

Wrangling pharma: ECAB

In 2013 ECAB published a review and analysis of ECAB, outlining a feasible model for patient community involvement within the field of research within the framework of the NEAT project called 'The impatient patient: from anger to activism.'

EATG has shown over the years that it is possible to cooperate with the pharmaceutical industry in a meaningful and productive way, and that an ethical stance and consistent work will prevent becoming a slave to industry money while accepting donations.

ECAB continues to provide important forums for discussion and liaison with drug companies in order to advocate for treatment availability. Indeed, the ECAB model is a key achievement and is now used not only in other diseases such as TB and hepatitis but also in other areas such as diagnostics or generics. The concept that patients are actively involved in the process



of pharmaceutical development and biomedical research not simply as passive participants of clinical trials but rather as active advisors and consultants, is still relatively new but no longer unusual.¹⁷ In the last five years ECAB has continued to provide a core connection between the community and pharma. The model demonstrates that the community learn and get their 'teeth into hard subjects', taking a lead on issues impacting on them directly, for example appraising clinical trials.

The focus on science and innovation is strong in ECAB and for the past few years EATG has engaged in a number of projects such as CHAARM, ECRAN, and NEAT. One of these, the EmERGE project (Evaluating mHealth Technology In HIV To Improve Empowerment And Healthcare Utilisation: Research And Innovation To Generate Evidence For Personalised Care) has the aim to develop an mHealth platform to enable self-management of HIV in patients with stable disease. The

platform will provide users with mobile device applications that interface securely with relevant medical data and facilitate remote access to key healthcare providers. Led by the University of Sussex, UK, this is one of a number of academic projects with which EATG is working.

As of 2017, ECAB holds around 5 meetings per year – three for HIV and two for HCV – and the EATG notion that 'expert patients' are able to challenge drug companies on what is best for the community remains rare in the health sector. ECAB is also beginning to address additional themes such as diagnostics. In 2016 22 EATG delegates and community representatives attended the first thematic ECAB conference on diagnostics, held from 17-19 June in Bologna where community members discussed possible solutions to perform (rapid) point-of-care (POC) testing and/or screening for HIV and other infectious diseases in community settings.¹⁸

17 EATG: The Impatient Patient: from Anger to Activism. Bereczky T. (2013) The Impatient Patient – A discussion of patient involvement in novel forms of knowledge production - a case study of the European Community Advisory Board on HIV/AIDS. Socio.hu, Special issue in English 1, 1-21. <http://dx.doi.org/10.18030/socio.hu.2013en.1>

18 Source: EATG Office report June 2016

KEY EXAMPLE OF SIGNIFICANT CHANGE: PROTOCOLS

PROTOCOLS 1: Going back to when I was on BoD, our protocol review team had an effective job of working with US colleagues (ATAC) to make sure one drug company changed their research protocol to benefit patients.

At one point [one drug company] was refusing to change their protocols. We said the process shouldn't have got to this stage without consultation. In the end they did change so we had an impact on the protocol review and the science - BUT another company still doesn't let us review. These are protocols for trials, and we were instrumental in changing some of them. For example, they used to have low cut off level for CD4. We proposed that this is a medical trial, and if dealing with people who have been diagnosed late with a low CD4 count they should be put immediately onto the best treatment rather than enrolling in a trial (which would take time). We suggested there should be no one with CD4 count of less than 250 enrolled. In the end, this was good for [the drug company] as the results were more positive than others because there were not so many people enrolled with a low CD4. Part of their reluctance was that in US, where the health system is screwed up, at the time it was an easy way to get treatment.

Brian West, Scotland



PROTOCOLS 2: If we don't like it we can get things changed during protocol reviews, and access to drugs when trials have finished. Until drugs are available we need to make sure people keep the drugs [they were provided with during the trial]. It's important to highlight the impact of protocol reviews. We need information on trial participants, their rights, drugs used and the dosage, and the whole trial structure. If we can change this, then it means people who need this treatment get it. People don't have to wait. For example, due to a co-infection a lot of people were excluded from a trial, but after some recommendations and key changes they are now included into the trial. One case stands out - HIV and TB co-infection. There were so many exclusion criteria, but we got most of them out. It took a lot of work but we went back to look at the TB guidelines that were linked with HIV. Hepatitis B and C were now included, people with low CD4 counts were included. One of aims of the protocol reviews is to get more people on treatment.

Damian Kelly, UK

KEY: EUPATI

EATG is involved in other projects that focus especially on developing the expert patient. The European Patients' Academy for Therapeutic Innovation EUPATI (www.eupati.eu) was established in 2012 as part of the European Union's Innovative Medicines Initiative. "It aimed to trigger a major rethink in the way patients and the public understand the medicines development process and their own involvement therein. Armed with a deeper understanding, patient experts and advocates will be empowered to work effectively with the relevant authorities, healthcare professionals and industry to influence the medicines development process for the benefit of patients." – states the project's closing report from early 2017. EUPATI also continues as a public-private partnership led by the European Patients' Forum (EPF).

The key achievements of EUPATI include the development and organisation of two patient expert courses for a total of 96 patient advocates from a wide array of disease areas, who have gone through a rigorous online and offline training course of 14 months to become trained experts in medicines development and clinical trials, so that they can participate as equal partners in data safety monitoring boards, ethics committees, trial design and regulatory processes. The third training course will start in September 2017. Another key output

has been the EUPATI Toolbox, which is a collection of several thousand pages of educational materials and encyclopaedic knowledge about medicines development and clinical trials, and has reached more than 200,000 individual users by mid-2017. EUPATI has also developed guidance documents for the interactions of the various stakeholders in the biomedical research and regulatory processes.

Essentially an educational project, EUPATI has been successful in bringing together all four stakeholders involved in the medicines research and development process: the regulators, the pharmaceutical industry, patients and academia. All decision making and content production bodies and committees of EUPATI have been based on the parity principle of these four partners.

So far, one EATG member has graduated from the patient expert course. EATG members Koen Block and David Haerry were members of the EUPATI Executive Committee in its first stage. David Haerry was also the internal project leader for EUPATI, while Scientific Officer Giorgio Barbareschi was leading the sustainability work package. Giulio Corbelli and Tamás Bereczky were members of the EUPATI editorial board. Tamás produced the advocacy training modules for the patient expert training course, while Giulio also worked as trainer and facilitator in the face-to-face

training events. In stage two, Giulio remains on the editorial board and the course faculty, while Tamás is the Steering Group member and communications lead on behalf of EATG. Several EATG members have worked as content developers and reviewers during the project.

In terms of volume and time, EUPATI has been one of the largest and most comprehensive transversal projects that EATG has been involved in in the last 5 years, and it has also been one the first major EC-funded projects next to OptTEST.



Impact: highlights

Prevention

The Policy Working Group continues to be an important forum for discussing key issues. In the future an avenue to explore might include working closely with the BoD and the office to clarify and promote policy positions that EATG can adopt. This was illustrated by the PrEP discussions, and cross-cutting issue-based working is much more likely in the next five years. Such a move, especially close collaboration with other working groups, would also enable the strategic allocation of EATG's limited resources and EATG governance frameworks.

PrEP is not without controversy. Both inside and outside EATG there was some hesitation about biomedical prevention and concern that it would influence treatment rollout, increase the risk of toxicity and stigmatisation of PrEP users, or lead to a reduction in condom use. But EATG's position is clear, and for advocates like Gus Cairns, "biomedicine is an answer and not a cause," and that the proven benefits of PrEP outweigh potential, and as yet unconfirmed, risks.

EATG's first position paper on prevention was released in 2009, although the group has been engaged with various prevention technologies since 2001, when ECAB meetings addressed **vaccines**, forming the basis for a booklet that the group published two years later.



In October 2003, EATG presented a poster at the 9th European AIDS Conference in Warsaw, summarising information from the European Therapeutic Vaccine Trials Database. In October 2005, **the New Preventive Technologies Working Group** (originally the Vaccine Working Group, formed in 2002), together with the recently formed **Eastern States Working Group**, sponsored a training workshop on HIV vaccine clinical trials in eastern Europe. The New Technologies group also worked with ECAB to organise an ECAB meeting on **microbicides** in December 2005. Finally, in 2010, as the community partner in the **EUROPRISE consortium**, EATG organised a multi-stakeholder community meeting on PrEP research and development priorities. It also developed a series of multilingual patient-friendly information leaflets

to help potential study subjects make an informed decision about enrolling in the NEAT 001 trial that started recruiting patients in 2010.

Since then, a number of issues gained particular prominence in the prevention debate, such as PrEP, therapeutic vaccines, cure strategies, and expanding access to microbicides. In 2015, EATG released its second position paper reflecting the consensus of the EATG membership on HIV prevention, particularly in relation to new advancements in the field.¹⁹ EATG's commitment to prevention included leading a satellite session at the 2014 International HIV/AIDS Conference in Melbourne, where Brian West chaired a meeting on 'The use of antiretroviral treatment for prevention: the role of community, tensions and ways forward', illustrating EATG's role in connecting

communities with treatment as prevention initiatives. The 2014 conference provided an opportunity for the release of a Community Consensus Statement from community organisations and actors, and at the 2016 GA Prevention Coordinator Gus Cairns outlined the possibilities – and challenges – within the HIV landscape, especially for locking prevention – and PrEP – into EATG’s core advocacy contribution.

PrEP is now a key strand of EATG’s work, but initial thinking on treatment as prevention was evident from 2010.



The role we are playing in biomedical prevention is increasing – we have this capacity in advocacy. If there is an advocacy action to be planned, people are happy to collaborate with us because we can put it in place – e.g. EATG members were sitting at EMA [and played an important role]. We tried to launch mobilisation for access to PrEP in Europe, [at a time the] EMA was not clear.”

Giulio Corbelli, Italy



At that time, in 2010, before integrase inhibitors and when lots of regimes were substandard, we had a very forward thinking meeting discussing PrEP and what had been done so far. This was before the IPREX study confirmed PrEP could work. EATG took a lead among HIV organisations in Europe in talking to researchers about the importance of involving the community in prevention trials, and in talking to communities and educating fellow activists about issues particularly important in prevention trials that didn’t apply so much to treatment, such as the involvement of non-diagnosed and non-positive communities. Much like vaccine science.

Gus Cairns, UK

To broaden the application of PrEP in the last few years, EATG’s advocacy aimed at two targets: pharma to support *Truvada®* as a treatment for PrEP, and the EMA which was, initially, reluctant to accept this as a treatment indication. EATG promoted PrEP heavily in many forums, and as of 2017 PrEP is being rolled out in many more European countries. Though not the only organisation involved, EATG’s strong connection at the European governance level is likely to have had significant impact. According to Kevin Fisher, of AVAC, “EATG was instrumental in [forcing] the European Medicines Agency to become proactive on PrEP, which was crucially important.” Studies released in 2017 continue to confirm that, even in lower-middle-income

countries (LMIC), despite low levels of awareness of PrEP, MSM are willing to use it if they are supported appropriately to deal with a range of individual, social, and structural barriers.²⁰ Indeed, according to AVAC, when EATG became committed to PrEP, there “was nothing else really in Europe at this time.” With EATG, alongside other organisations, promoting it, PrEP became dominant in the prevention discourse.

EATG continues to advocate for better access to PrEP. In 2017 EATG and partner organisations applied pressure on Gilead to make *Truvada®* accessible at ‘generic prices’ across Europe by surrendering its remaining patent rights.²¹ Discussions are continuing, but EATG with its partners remains committed to ensuring *Truvada®* for PrEP is available where needed.

A somehow related prevention focus for EATG is the European HIV and Hepatitis Testing, and as a member of the European HIV/HCV Testing week working group, EATG supports HIV in Europe in its advocacy role.

EATG is an active contributor in the European HIV Vaccine Alliance (EHVA), an EU platform for the discovery and evaluation of novel prophylactic and therapeutic vaccine candidates.²²

The use of microbicides is another prevention area highlighted by EATG. Support for microbicides is important, according to AVAC, who co-sponsored two prevention meetings with EATG; “at the second prevention meeting the microbicide community was engaging because EATG had been supportive.” This also applies to the promotion of PrEP that, again according to AVAC and with reference to the same meeting, “the issue of the PROUD study and a lot of interest in PrEP [was evident]. EATG became a focal point for conversations about PrEP in Europe.”

Kevin Fisher, AVAC



KEY EXAMPLE OF SIGNIFICANT CHANGE: PrEP

Despite the fact there is a huge delay of PrEP becoming available all over Europe, EATG has done as much as it was possible to achieve. EATG put pressure on one company to convince them to file for a particular PrEP indication. EATG also put pressure on the European Medicines Agency that at the time was reluctant in extending the indication. EATG advocated for raising the importance of PrEP as a prevention strategy, and we are starting to see results. In the last couple of months countries have made PrEP available. We are finally seeing the fruits of advocacy. I am confident that in the next year more EU countries will make it available. EATG contributed significantly, together with other groups.

Andrej Senih, Macedonia



PERSONAL STORY: PETER WIESSNER

I've been working in Germany for AIDS Hilfe organisations for more than 25 years. At a certain point, I became very interested in getting more involved with HIV issues at international level. It happened during a training that I facilitated that I met a German EATG member who introduced me to the organisation. The EATG provided me access to international conferences and debates.

I've seen a lot of changes in the past decades. Meetings of the PWG used to occasionally descend into shouting and abuse. But HIV has become less of a dramatic, desperate disease than it once was. And people eventually realise that you can't keep screaming year after year.

A valuable experience as an active member so far was the co-organisation of a two-day conference on migrants' access to HIV-treatment. The conference was very successful - I found it remarkable that the organisation was so willing to finance and otherwise support it. Other remarkable experiences relate to sessions and workshops that I organised on behalf of the EATG with partners and colleagues from PICUM (Platform for International Cooperation on Undocumented Migrants) or Doctors of the World. Being a member of the EATG can be a fun and a learning experience, especially when you leave the screen of your computer, or rise up from your couch and get actively involved.

I believe the biggest challenge ahead for us will be in staying honest, fresh and alert to Europe's changing new realities. The right balance is important: Some use the EATG more for personal, some for professional purposes or their career, regarding the membership composure, a right mixture between members living with, or affected by HIV seems me to be another big challenge, which we have to meet.



KEY EXAMPLE OF SIGNIFICANT CHANGE: European Medicines Agency (EMA)



One drug company was reluctant to promote a specific medication for PrEP. It had gone through the FDA in the US but given initial bad vibes from the EMA, who thought the trial data was weak. We had meetings at Melbourne AIDS conference with the company, suggesting they should go to the EMA, as a trial in London had been successful. Other studies confirming benefit included PROUD and IPERGAY studies, so the EMA may change their view. Eventually, in 2016, it was taken to the EMA and as a result it was accepted in Scotland and other countries, including Spain. It was an important procedural step, and EATG pushing the drug company to take it to the EMA was a key part of the process. Without EATG, especially ECAB, the BoD, and the Prevention Coordinator at the European level, this wouldn't have happened.

Brian West, Scotland



Hepatitis

EATG's focus is specifically HIV, but HCV and TB, as co-infections, feature as important components of the group's activities. Access to treatment for HCV, for example, has been in the EATG narrative for a number of years. Patient activism in the HCV space was in some ways less well established than HIV, and for EATG this offered opportunities to - according to Juergen Rockstroh - "move the HCV agenda on to the table of policy makers and intensify the treatment access discussions in Europe." Indeed, for Juergen, "EATG has actively worked with other organisations such as IAS, HIV in Europe, and ELPA, as well as other stakeholders, to help in the fight for universal HCV treatment access.

Moreover, EATG has played a strong role in providing sufficient education around viral hepatitis to strengthen the role of community involvement." Since 2012 HCV has morphed into a condition that can be easy to treat and test for. This has changed the dynamic and the paradigm significantly, and EATG has driven integration of HCV with HIV and TB at the European level, as shown now in the new format of the Civil Society Forum. This has been crucial to ensure they are still addressed in a political context that edges towards broad health agendas and away from a focus on specific diseases.

The Sitges meetings

The so-called Sitges Conference, a multi-stakeholder meeting that



is celebrating its 10th anniversary in 2017, is a particularly powerful forum for discussing approaches to the care and support of people co-infected with HIV and viral hepatitis. Initially held in Sitges, southern Spain, the conference brings together researchers, activists, affected people, and health care workers. The broad purpose of Sitges was to advance HCV drug development and access to treatment through clinical trials that are well-designed, ethical, clinically relevant and inclusive of people who are HIV/HCV co-infected, current and former drug users, people living with other medical or psychiatric conditions, transplant candidates and recipients, people living with advanced liver disease, and members of other marginalised and underrepresented communities. The event is held over three days, during which community members meet to discuss recent scientific hepatitis information and agree on priorities.

EATG continues to organise these symposia every year, and they represent a major area of focus for the group. As a result of early Sitges meetings, the 2009 GA provided the PWG and ECAB with a mandate to create a joint Hepatitis C Taskforce to develop and implement a plan for improving access to hepatitis C services, particularly for people co-infected with HIV, and targeting stigmatised groups and countries in eastern Europe and central Asia.

Sitges remains a significant meeting of its kind. For example, before Sitges I, new HCV drugs were not tested on co-infected people. In addition, representatives from the HIV and HCV communities work together towards goals common for people living with hepatitis C, and HIV/HCV co-infection, and the meetings offer an opportunity to share the latest data and forge community consensus among multiple stakeholders. A positive outcome of Sitges III was the formation of HCAB, a network of international activists from the HCV and HIV/HCV community who provide a mechanism through which activists can work with companies on their HCV drug development programmes, review protocols and participate in investigator meetings. In some countries, HCAB provides early access to experimental HCV drugs. EATG's role in raising issues as a community priority in core forums is vital.

The most recent Sitges event in 2016, held in Tbilisi, Georgia, reflected its importance.²⁴ Focusing on access to direct-acting antivirals (DAAs) for hepatitis C (HCV) in EECA - due to the scale of the epidemic and limited access to highly effective therapy in those regions - the event included contributions from major pharmaceutical companies, the WHO, Medicines Patent Pool, the National Centre for Disease Control and Public Health of



Georgia, and participants from a range of national-level civil society organisations. As with all previous events, the meeting produced recommendations for stakeholders and provided an excellent example of EATG's leadership, working in partnership with local and European-wide organisations on an inclusive and targeted intervention to address a current core need in the HIV sector.

Another mechanism illustrating EATG's commitment to treatment access, and the value of a member forum, was highlighted in 2017. Following the release of a Cochrane review, it was suggested that direct action agents for the treatment of hepatitis treatments were not clinically effective and did not provide an economically viable treatment option.²⁵ Over a period

of days EATG's membership list provided a community response to the review, highlighting its weaknesses with a core message: Pan-European and global networks of communities of people living with and affected by hepatitis C (HCV) and HIV point out that current direct acting agent (DAA) treatment options against hepatitis C infection, which provide a final cure to 95-97% of patients carrying HCV, are effective and useful from an epidemiological and public health perspective.²⁶

In the past few years increased attention has been on hepatitis diagnostics and other types of hepatitis (HAV, HBV, HDV), especially linked to outbreaks within the MSM community.

24 See meeting report: Tbilisi/Sitges IX Meeting: Policy Meeting On Access To Direct-Acting Antivirals In eastern Europe And central Asia [December 2016]

25 For original Cochrane review: Jakobsen JC, Nielsen EE, Feinberg J, et al. Direct-acting antivirals for chronic hepatitis C. Cochrane Database of Systematic Reviews 2017, Issue 6. Art. No.: CD012143. DOI: 10.1002/14651858.CD012143.pub2.

26 Full text of EATG response: www.eatg.org/news/eatg-is-concerned-by-the-cochrane-review-of-daa-treatment-against-hcv-infection

Tuberculosis (TB)



Despite notable progress in the past decade, tuberculosis (TB) remains a public health concern in most of the countries within the WHO European Region. EU/EEA countries have a significant number of TB cases among vulnerable population groups, such as people of foreign origin and prisoners.

For many years, EATG has been active on TB as co-infection. In 2002 ECAB organised its first training on TB. ECAB organised several thematic TB meetings focusing on the clinical aspects of TB and clinical research on TB/HIV co-infection, designed to serve as training for the European patient community and to help develop an advocacy agenda for them in the WHO European Region.

EATG contributes to TB Online together 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.²⁷ TB Online is a website for activists, patients, health workers and researchers, which disseminates knowledge and promotes advocacy to end the worldwide epidemic of TB. The site is run by the Global Tuberculosis Community Advisory Board (TB CAB) and is dedicated to increasing community involvement in TB research and mobilising political will to develop and make TB diagnostics and treatments available.

With support of a TB portfolio and portfolio coordinator, EATG organised a meeting in 2017 on the research needs related to TB as co-infection, which also resulted in a meeting at the Belgian senate.

European policy

EATG's policy focus continues to be evident across the EATG's portfolio. It impacts on a range of activities including pricing, treatment accessibility, HIV testing, and prevention. EATG's policy advocacy has been a component in keeping HIV on the agenda at the EU level, developing consensus statements, for example on TasP in 2014, contributing towards the European HIV testing week, and responding to increased criminalisation of HIV by raising this concern at regional meetings, such as the International AIDS Society conferences. A standout project in which EATG is involved is OptTest. Launched in 2014, OptTest aims to reduce barriers to HIV testing and improve early diagnosis and care of PLHIV in Europe. This offers an important opportunity for EATG to shape European testing guidelines, and share best practices in community engagement, such as at the 2016 meeting of the EU Fundamental Rights Agency, which aims to increase LGBTI access to health services. available.

With support of a TB portfolio and portfolio coordinator, EATG organised a meeting in 2017 on the research needs related to TB as co-infection, which also resulted in a meeting at the Belgian senate.

Civil Society Forum

A core component of EATG's policy impact at the European level is through the EU Civil Society Forum (CSF) on HIV, TB, and viral hepatitis.

The EU Civil Society Forum (CSF) on HIV, TB and viral hepatitis is a civil society expert's forum, with members selected by the EC following a call for applications. It aims to facilitate the participation of NGOs and networks, including those representing people living with HIV/AIDS, viral hepatitis and tuberculosis, in European policy development and implementation, and exchange information and knowledge. It also serves as a civil society consultation partner for the EU HIV/AIDS Think Tank (an expert group comprising representatives of national health authorities in EU Member States and selected neighbouring countries). It provides a space with all players for setting the agenda, and as co-chairs on the CSF EATG, together with AAE and alongside the other organisations, have a direct conduit to the European regional policy agenda. EATG was re-elected to be part of the CSF's coordination team in 2017.

The CSF was established in response to the Dublin declaration from 2004 that required the governments of Europe to monitor the implementation of the commitments, uptake and scale-up of HIV services. Being engaged with such an important body such as the Civil Society Forum of the European Commission on HIV/AIDS, Viral Hepatitis and Tuberculosis is key, and forms an important component of EATG's policy work, and is a workable model for facilitating interactions between civil society and government. For one member, "Sometimes the community is more knowledgeable than the actual people from governments." The CSF is an informal body, and the Think Tank (see box) a formal body,



voice at the European level is tremendous. This is something that can't be understated.

There are not that many organisations that do this.

Michael Krone, AAE



Personal and professional impact

EATG is an organisation that, by definition, spans the European region, encompassing over 50 countries, multiple manifestations of the HIV epidemic, and a range of political and cultural contexts. There are common interests, however. EATG is in a position to develop collaborations and knowledge sharing and, for one member, “It is great to meet others involved in issues of screening, care, and treatment in Europe. Often the issues we face are similar and there are different strategies used that can be shared.”

through which the CSF has input into the agenda. Joint HIV, TB, and hepatitis communication plans are advocated within the Think Tank. Other organisations are also represented there, including those involved with children, IDU, and other communities. As a co-chair of the CSF, EATG has a direct link between its members and policy level initiatives in the Member States of the Europe. The CSF forms an advisory board to the European Commission on the implementation of monitoring, communications, and action plans for HIV. It also provides a vital opportunity for raising issues that may seem self-evident to members of the community, but are not perhaps so evident to politicians, researchers, and epidemiologists working at the somewhat abstract level of European policy. For the AAE’s Michael Krone, “This is what EATG are good at.”

A key part of the CSF’s work has been contributing towards developing a new EU policy framework and strategy for HIV. When the previous strategy came to an end in 2014 there was a push from civil society to ensure the focus on HIV continued. The CSF (together with EATG) was well-placed to take a leading role, and the CSF continues to provide a vital forum for civil society input through what is sometimes called a ‘European democratic way’. It speaks truth to

power.

And the CSF is still evolving, in part to meet the threat of HIV falling down on the policy agenda and also to expand the policy framework beyond HIV. As co-chair EATG has been leading civil society’s demand for the integration of HIV, TB, viral hepatitis, and STIs - an amalgamation that has largely been achieved.

In Macedonia, one local organisation has used the EATG internal model as a template – “We learnt a lot about how to structure our organisation to ensure it is about the community. For example, around the governance structure, the importance of having an assembly of members who have a delegation of authority, an office, a board, and internal policies and procedures to avoid conflicts of interests and be aware of them and talk openly about them. These things should always come from the membership.”

Andrej Senih, Macedonia





For a member from Italy, being part of EATG meant being “able to raise issues and change direction in our activities. For example, we have started community-based testing on a regular basis, we have debated on PrEP, and pushed and obtained the possibility of having self-testing kits sold in Italian pharmacies.” Another member, responding to a survey in 2017, says the following: “Being a member of EATG has changed me in every possible way. EATG has become a place I can meet like-minded people (more or less) where we focus on our commonalities and work together (more or less) to achieve a greater cause.” A member from Slovenia stated in 2017 that, EATG “has helped me develop my competencies, which helped me progress with my work and activities at the local and EU level.”

At the national or organisational level EATG’s activities are predicated on empowering advocacy and

Being a member of EATG has changed me in every possible way. EATG has become a place I can meet like-minded people where we focus on our commonalities and work together (more or less) to achieve a greater cause. It has made me realise that people all over the world are pretty much asking for the same things: safety, love, and compassion even if they use different ways to achieve those. For me, the most challenging part has been learning to use a political language (I am still far from it) and set political goals, which can take years and years to achieve. So I am learning the art of patience.

Christina Antoniadi, Greece

increasing access to treatment and care for PLHIV, and it is critical to explore the extent to which organisations and individuals have benefited from the group.

For example, in Italy, members discussing PrEP and community testing and, in Romania, highlighting issues at policy levels around stock outs and addressing HIV in young people, all suggest that EATG is able to provide support at the local level. Indeed, for countries with weakened health systems, or gaps in effective legislative and policy frameworks, EATG offers access to information and resources that can speed up the development of much-needed support networks for PLHIV. For a member from Romania, responding to a membership survey in 2017, “I was the only Romanian EATG representative for two years, and as member I had the opportunity to participate to the ECAB meetings and other important conferences,

and translate and disseminate medical information in my country.”

Bringing people into the Ageing Conferences, or the Sitges hepatitis meetings, facilitates a rapid form of capacity building. For one member, “It was great to receive capacity building, learning, and then be able to inform those living with [hepatitis] in my country.” And for a Romanian participant, “[participants at the ageing conference had the] opportunity to better know each other, to discuss with doctors who gave presentations at the conference [and] inform them about the challenges and needs; to improve the doctor-patient relationship.” From Tajikistan, one member stated that, “My director [attended] the STEP-UP Academy and is now a full member of EATG. I studied at STEP-UP at the academy and received a grant, according to which I transferred the School for MSM to PLHIV.”

4. Where are we going? Unique organisation, unique future challenges

“Future’ is inherently plural.” (William Gibson)

We really need EATG in Europe. It remains the only HIV activist network in Europe. But I also think it shouldn't forget its activist roots. All HIV advocates need the engagement with LGTI across Europe. This is what happened successfully in France when they got PrEP on the agenda – it was through the LGBTI community in France. A challenge for EATG will be how to keep focus on the big, broad mission of tacking HIV, TB and HCV across Europe, whilst at the same time maintaining a concrete and specific focus on the epidemic in MSM and a perspective on countries where there is no political leadership or community awareness.

**Henning Mikkelsen,
formerly UNAIDS**

Changes in the political landscape, with stronger right wing or fundamentalist representation, usually come with increased risk for stigmatisation and criminalisation of vulnerable groups that urgently need help to keep their rights protected.

**Juergen Rockstroh,
STEP UP External trainer,
member EATG External Advisory Board**



EATG is doing a great job! Just continue your mission. It is not over yet. There is always room for improvement. We could do more: to introduce PrEP faster in EU and also other tools to stop the spread of HIV among MSM in Europe; keep advocating for the best treatment options; for finding the cure for HIV, HBV, and challenging health inequalities.

**Respondent,
Membership Survey 2017**

In the next five years EATG is likely to continue to diversify its membership and geographical reach, and to strengthen its advocacy work through project-focused initiatives that provide income for the organisation, drawing on broad based membership expertise. Many of the challenges EATG is facing are familiar, and for many current members it is also important to maintain elements of old style activism, the bedrock of advocacy.

What are the challenges – and opportunities – facing EATG now? EATG's long-term strategy (2016-2018) identifies a number of core areas, and this section reflects its strategic goals.

Diversity: assessing gaps and specific key populations

EATG is diversifying its membership, geographical reach, and topic focus. For some, this may feel like a move away from a feeling of 'family' that was strong in EATG's early days – a necessity at the time. Early members remain strongly connected, perhaps more recent members less so. With HIV moving away in some areas from an 'emergency' status, increasing criminalisation and stigma in others, and complex picture of medication provision across the region, there has inevitably been an impact on the nature of EATG, both internally and externally.

Geographically, broadening attention eastwards is strategic, and interventions are likely to address problems that were faced in the West a decade ago; access, testing, and health system gaps. The focus should always be on what is actually needed, on listening to the members in the region. As EATG engages with other, related, diseases such as TB and HCV, it's also important that the core populations affected by HIV are not forgotten. Human rights for LGBTI, the enhanced risk of HIV in certain groups and particular countries will remain a vital area for advocacy in which EATG can play a key role.



EATG has an important role to play to help keep the HIV crisis in eastern Europe and central Asia on the European and global agendas. Communities in those countries are pushing their governments to fund prevention and treatment. Until they are successful, we must continue to push donors to keep money flowing to the region and push the pharmaceutical industry to stop taking so much money out of it. I hope we will also unite with other regions like Asia and South America, where the middle-income countries are suffering a similar crisis, to boldly call for a more humane response. I would like to see EATG be bolder in its call for access alongside call for price reduction. We should not compromise when it comes to pharmaceutical industry profits. People are still dying in our middle-income countries and industry profits are partially to blame.

Shona Schonning

EATG is indeed in a strong position to push for better treatment access into the east and central Asia, and can be a significant player. If not, countries such as Russia are likely to continue to have expanded epidemics.

EATG can support from a grassroots level, with the overall aim of reaching regional targets, such as 90-90-90

²⁹,

and 95-95-95, the ultimate target for

2030³⁰. These targets should not be simply aspirational, but achievable. Where even a 4th 90 is being discussed in some western countries (beyond detectable quality of life), major investments still need to be done to improve different elements of the cascades of care in central and eastern Europe to bridge the current gaps.



Apostolos Kalogiannis

29 UNAIDS 90-90-90: <http://www.unaids.org/en/resources/documents/2017/90-90-90>

30 UNAIDS 95-95-95: http://www.unaids.org/sites/default/files/media_asset/JC2686_WAD2014report_en.pdf



We could aim to be the first continent to achieve no new transmissions. But that will take will and a big push from everyone, not just a few. The future must be about the care people receive, and the laws around HIV – what will they look like? With cure research, what about when someone goes through a programme, but after 2 years has a rebound, where do they stand in the law if they transmit? There is also stigma, and if someone always has to say, “I was HIV positive,” the stigma will never go away. We need to get lawmakers to look at what this means. Will people be given protection? Will I have to disclose?

Damian Kelly, UK

Another area, in which EATG provides support, rather than a lead, is that of harm reduction for drug users. EATG is in a strong position to mobilise civil society to become more coordinated in its efforts to increase funding and support for harm reduction, and this would be consistent with expansion eastwards and the specific epidemiology of HIV and injecting drug use. EATG contributes to statements with the Eurasian Harm Reduction Network, (EHRN) for example, and provides input in the European policy context, such as membership of the EU Civil Society Forum on Drugs, CSF on drugs. But is there more to do?

For Anna Dovbakh:

I understand a priority focus is treatment, and testing – we certainly need to fight for treatment. But this is a medicalisation of the HIV response, and is a challenge. The temptation is to go for ART schemas and promoting PrEP, instead of prevention that addresses the needs of specific communities. That's the most challenging, and I hope EATG will mobilise national forces for advocacy to address shortcomings in harm reduction.

Anna Dovbakh, formerly EHRN, Lithuania



Access: pricing, affordability, and human rights

EATG has played a large part in putting pressure on pharma with regard to pricing, and especially treatment for HCV and for PrEP. This has gained the attention of drug companies, and EATG can provide detailed arguments for the EU and EMA so that they can also engage with pharma on pricing, from a fully informed position. Some of EATG's work requires direct contact with EU through CSF, and some involves influence more generally through open letters. In some settings, and for Gus Cairns (UK), "EATG is able to push above its weight, especially around [pricing] policy."

Pricing issues in the East are particularly acute, and the search for generic alternatives has been more prominent in the East than other parts of Europe; any health system that is required to provide universal access is going to be affected significantly by price. According to a Lithuanian EATG member commenting in 2017: "I was involved with building the knowledge of eastern Europe and central Asia access to treatment, using global materials, and adapting to Russian language. So eastern Europe gained better understanding on pricing, [but] we activists were [historically] the last to understand this is an issue. Not sure if this is through better understanding of patent protection, but pricing is something



that people feel similar to HIV and TB treatment drugs. [Advocates] started understanding overall how pricing affects health budgets."

The implication of this is that if pricing is reduced for HIV medication, then the provision of other treatments becomes easier. There is certainly a growing cohort of people needing treatment, and therefore health systems need to consider the burden and the capacity to pay. EATG can shape its advocacy to work towards a better quality of treatment.

In popular culture, Groundhog Day refers to an endlessly recurring phenomenon. For many in the HIV sector, especially those involved or affected from the early days, we see progress on important issues - such as reduced HIV stigma, and

increased awareness of HIV risk - threatened by marked regression on a seemingly cyclical basis. It is our Groundhog Day. For the AAE's Michael Krone, this is a significant challenge for EATG: "We all work against discrimination, stigma, and criminalisation of specific key populations in different countries. This remains on agenda because the political climate is not getting better. I'm an old man and I feel sometimes that things that I thought were understood 30 years ago have to be explained again and again." Studies confirm stigma and discrimination have significant negative effect on access to HIV services, adding to a matrix of barriers facing PLHIV and those at risk, and EATG is well-positioned to keep promoting this key message and help prevent policy regression.

Renewing activism: and not forgetting institutional memory

Loss of institutional memory is coupled with the move away from 'AIDS exceptionalism'. In general terms, EATG will always face the challenge of declining interest in HIV as a discrete policy focus, and while it is progressive to broaden the focus from HIV towards other related diseases – reflected in the recent SDGs replacing MDGs, and promoting 'universal coverage' for care and support – the heritage from work on HIV and AIDS is invaluable. Lessons learned by the community, advocates, and PLHIV themselves drove many of the key developments in the sector (more so, initially, than national and regional policies). Is there a need for succession planning, or for educating nascent activists about the early days of HIV activism? EATG has much to offer, as it is doing with the current EUROPACH project, and can dig deep into its wealth of experience and not being afraid of 'getting its hands dirty'. Old-school activism still has a place.

A core component for strengthening EATG's activism is through capacity building and expanding the knowledge and skills of the entire membership. The membership currently consists of some who are highly experienced, some new to the HIV sector, and others affected directly by the virus but not working in the field. EATG can seek ways to ensure that members are empowered to a high level and are able to influence their specific contexts, but this requires thorough and strategic work by EATG to target support and build capacity. For example, patients in the west of Europe will have different needs and challenges from those in the east, where accessing any treatment can be a challenge. What do members in different countries require? EATG cannot risk parachuting specialists in to provide, for example, training that isn't needed, or has the wrong priorities. EATG cannot be 'colonial'.

Linkage: maximising impact through multi-stakeholder strategic relationships

Strategic approaches to coordinating with other organisations, especially those in the European east and central Asia, from where many new members originate, will become increasingly prominent. This is especially the case where Global Fund support is transitioning to national level. EATG has little to do with the Global Fund currently, but is liaising with organisations that could expand its reach and allow targeted support during the transition period.

EATG, with its rich institutional memory and empowered membership is in a powerful position to work with other patient groups to share information on advocacy skills and policy influence. This could be done through EUPATI or other projects or networks where HIV is but one of a number of diseases that affect representatives.



Internal structures and being ‘fit for purpose’

In some ways, a purely vertical approach to working groups has outgrown itself to become a more coordinated, horizontal structure which ensures the sharing of science, policy, and training within EATG’s work. As a result, a more ‘project led’ approach to EATG’s work is likely, in the future, to be implemented with a more transversal style in which contributions will be made from all working groups. This was demonstrated recently by PrEP, which was driven by input from all the working groups.

With ECAB, it is likely that there will be an opportunity to shift the focus to include not just scientific debates with pharma – which were vital for treatment-related discussions – but related issues, such as access in treatment-starved areas of Europe, and consideration of research protocols, something that has already been done. ECAB could conceivably become a ‘task force’ to focus on particular medicine-related questions, for example the likely increase of generics in the future. Perhaps most important, EATG needs to adapt and morph into a more streamlined, responsive system accountable to our funders and using advances in online systems to communicate and eliminate waste, so we get ‘more for less money’. This will include continuing to cover scientific and policy aspects of projects, findings ways to disseminate, capacity build, and share across all projects, without being restricted by silos.

There is a need for effective monitoring and evaluation (M&E), such as tracking actual achievements (outcomes) rather than simply noting activities. EATG is heavily involved at the policy level and undertakes a great deal of training, especially of late, likely to be of significant benefit to individuals. But what is the strategic impact? This need to know is recognised by the membership and as one member describes in 2017: “As far as significant developments, I would include the development of the long-term strategy and a strong commitment to develop a robust monitoring and evaluation system across the organisation.” Identifying achievements as not just activities, but impact on the lives of PLHIV (and delivering on the strategy), will be an increasing focus for EATG in the coming years.

Funding

As EATG seeks to address the need for funding to support its growing commitment, so the shift to the transversal project work which spans all EATG’s membership groups is increasingly necessary, and this requires transparency around project applications, as well as horizontal sharing and working.

Doing more with less, or creating enough success that funding follows. I’d like to see a clearer statement of WHO European needs, whether or not we have immediate plans for them: adequate prevention plans, safe testing for all, PrEP across Europe. HCV drugs access for all, TB treatment for all. [Also] demands for local organisation, for women, for sexual health and for social well being, local safe places for people to develop their knowledge and empowerment, sex workers, people who use drugs. [We could] respond to the greatest need.

Ben Collins, UK



Allocation of project work, which requires contribution from multiple working groups and members, will place new demands on EATG, especially in the selection of particular topic areas. EATG has significant expertise; and how best to capitalise on this in ways that address the strategy will be a key task for the management team in the coming years. As an example, EATG will continue to be involved in prevention, and it will be robust, but work will need to include thinking how to do prevention, for it addresses people not currently infected. In one sense, it challenges the HIV activism model to make conscious effort to make alliances with LGBTI organisations that may not previously have been involved with health-focused work.

The intended outcomes will of course be more strategic. It is likely that as patents expire and generic

There is still a lot of prevention work that needs to be done. Getting PrEP for Europe could take years. I hope they continue that work. I know funding is a struggle (mainly pharma), and pharma is fickle with their requirements. Pharma won't fund harm reduction work as much, and I hope funders like the Elton John Foundation [EJAF] could articulate a way to help EATG be seen as more than only treatment advocates.

Kevin Fisher, AVAC

medication is available in higher quantities, pharma funding may be affected. Developing relationships with other donors, and perhaps generic drug companies, is a key challenge for EATG in the coming years. EATG is indeed recognised as a strong advocate, and needs to be mindful of other strong advocates (e.g. UNAIDS) and to make sure that partnerships include sharing both ways. Groups in which EATG sits, for example AAE, UNAIDS, CSF, and EUPATI, will become increasingly vital partners in the future. Each country plays a significant role in funding local community services, and EATG could play a part in supporting advocacy to challenge local service commissioners to continue this funding. For Sini Pasanen of HIV Finland, "It's vital to ensure EATG doesn't just go where the donor or pharma money is... if funding is available for work in a particular country it may not reflect a particular role for EATG just because money is available. In every country there are always people who need something; sex workers, people who use drugs, and undocumented migrants, for example."

Patient representation

It's vital to ensure patient representation. For a patient-led organisation, one of EATG's key strengths has been to connect PLHIV - the patients - directly to policy-making bodies at the European level. As EATG diversifies that this connection can't be lost - representatives of patients should

never replace patients themselves. When EATG members attend meetings in other health areas, a dissonance is sadly evident. One member describes it this way:



I was in meetings where they say they are patient organisations, and recruited liaison officers who are responsible for keeping in touch with real patients. This is perverse. I don't want this happening with EATG - we will lose something essential which is to be in touch with the constituency.

Tamás Bereczky, Hungary

This also impacts on suitable recruitment to EATG, and Objective 14 in the long-term strategy states that EATG will 'establish a system of strategic recruitment with focus on diversity and representation'. Representation for EATG works in two directions: representing the patient community in European forums, and ensuring that new members are suitably representative of their own patient communities.

5. Final word

HIV is complex, diverse, and has an ever-changing context. Treatment development and availability, which was the core mission of EATG's launch in 1992, has morphed into a cluster of far broader issues such as treatment access and affordability, universal health coverage, and HIV's place in a wider spectrum of public health needs, as defined in the Sustainable Development Goals. As one member suggests, for EATG's optics there are:



“...good reasons for still looking at HIV through the lens of exceptionalism – for example social justice. However, it may be important for EATG to look also at broader health reform and ‘speak the language’ of universal health coverage. Energies to provide access – for example – in very low HIV prevalence areas will require different levels of intervention than areas with higher prevalence.”

Raminta Stuikyte, Lithuania

EATG is undoubtedly evolving. This is by necessity in response to external changes, and internally from an expanding and more diverse membership. Can EATG evolve sufficiently? The HIV world is changing rapidly, and issues are not the same for some countries. What is our space in the ‘new’ world where treatment is available but not all PLHIV have access? How can EATG deal with a global health context where HIV is not as prominently on health agendas as 10, or even five years ago? Quality of life issues for PLHIV – now that available treatment is proving successful – are becoming increasingly vital to address. These are the hopes and dreams of EATG.

By its nature, EATG is a ‘European’ phenomenon working to prioritise cooperation, share information, and work across the whole European region; and it can bring issues on the ground up to the regional level. For the AAE’s Michael Krone, “When you talk to a Checkpoint in Latvia that is being closed, for example, the EU can make a difference, and organisations like EATG and the AAE are involved from a civil society perspective. We still work on the ground and know what’s going on. If we don’t bring topics up at the EU level, people would never know about them.”

EATG has consolidated the voice of the patient community, and now more or less all international agencies and key political decision makers recognise that the participation of patient communities as advocates and leaders is essential to shape, implement, and design reforms and policies. This gives power to EATG.

Luis Mendao, Portugal



EATG was founded to improve the lives of people living with HIV, and it is they who are the organisation's bedrock. We have lost many friends since 1992, friends whose passion and commitment have empowered and inspired us. It is to their memory that we dedicate EATG's continuing work.

In Memoriam

Andreas Salmen (d: 1992)
Marc Regnard (d: 1992)
Michael Fischer (d: 1992)
Jan B. Haan (d: 1993)
Cord Ebeling (d: 1993)
Olov Wendelborg (1963-1994)
Nathalie Dagron (1960-1995)
Marina Bichetti (d: 1997)
Jørgen Haahr Kristensen (d: 1997)
Jürgen Poppinger (d: 1997)
Julio Silveira (d: 1997)
Jeannine van Woerkom (1954-1997)
Svetlana Denk (d: 2001)
Pedro Jorge Eduardo da Silva Santos (1962-2002)
Maurizio Pancanti (d: 2003)
Arjen Broekhuizen (1955-2004)
Eric J. Welling (1956-2004)
Albert Rúnar Aðalsteinsson (1950-2006)
François Wasserfallen (1962-2008)
Gideon Hirsch (1960-2008)
Roy Arad (1978-2010)
Jerzy Jurek Domaradzki (1949-2011)
Kees Rümke (1958 - 2014)
Bob Munk (1953-2015)
Paul Blanchard (1964 - 2016)

Glossary and acronyms

AAE	AIDS Action Europe (www.aidsactioneurope.org)
ART	anti-retroviral therapy for the treatment of HIV
AVAC	Global Advocacy for HIV Prevention (www.avac.org)
BME	Black and ethnic minority - technically, people of non-white descent
CA	Central Asia (e.g. Kazakhstan, Turkmenistan)
CAB	Community Advisory Board
Checkpoint	rapid HIV testing facility
COPE Project	Continuous Patient Education, a mechanism to fund the translation and adaptation of patient education materials related to HIV/AIDS treatment and policy
CSF	European Union Civil Society Forum, is an informal advisory body established by the European Commission that EATG co-chairs with AIDS Action Europe
DAA	direct acting antivirals; treatment to target hepatitis C virus
DDI	Didanosine, anti-HIV medication in the group of nucleoside reverse transcriptase inhibitors (NRTIs)
EC	European Commission
ECAB	European Community Advisory Board; EATG's high-level scientific platform that brings together civil society, scientific researchers, the pharmaceutical industry and international institutions to address key science and policy issues related to HIV and its main co-infections like hepatitis C or tuberculosis
EE	Eastern Europe (e.g. Ukraine, Belarus)
EECA	Eastern Europe and Central Asia
EHRN	Eurasian Harm Reduction Network
ELPA	European Liver Patients Association
EMA	European Medicines Agency, responsible for the scientific evaluation, supervision and safety monitoring of medicines in the EU
EU	European Union
GA	EATG General Assembly, the annual meeting of the EATG membership
GNP+	Global Network of People Living with HIV/AIDS
HCV	Hepatitis C virus

HIVACAR	HIVACAR is a pan-EU project that aims at changing the current paradigm of HIV treatment by obtaining a functional cure for HIV thanks to effectively targeting residual virus replication and viral reservoirs
IDU	Injecting drug user- this can be intravenous, or intramuscular
IAS	International AIDS Society
KAP	Key affected population; people who, for one reason or another, are more vulnerable to HIV infection
LGBTI	Lesbian, Gay, Bisexual, Transgender/Transsexual, and Intersexed
LMIC	Lower-middle-income country (e.g. Kosovo, Ukraine)
MDG	Millennium Development Goals; international agreements for health and social development that expired in 2015 (replaced by Sustainable Development Goals)
MSM	Men who have sex with men
OpTEST	Optimising Testing and Linkage to Care for HIV Across Europe, a project building on the 'HIV in Europe' platform. It aims to help reducing the number of undiagnosed people with HIV infection and newly diagnosed late presenters in the European regions and to promote timely treatment and care.
PLHIV	Person living with HIV
PrEP	Pre-exposure prophylaxis, a course of HIV drugs taken daily (for short periods) by HIV-negative people at greater risk of HIV to prevent infection
PWG	Policy Working Group; EATG's internal group that 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
SDG	Sustainable Development Goals; international agreements for health and social development, focusing on universal access, commencing in 2015 and expiring in 2030
THT	Terence Higgins Trust, the first HIV and AIDS organisation based in the UK
TasP	Treatment as prevention; HIV prevention methods and programmes using anti-retroviral treatment (ART) to decrease the risk of HIV transmission
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNODC	United Nations Office on Drugs and Crime
WHO	World Health Organisation

Board of directors EATG: 1992-2017

23 February 1992 (inaugural meeting, Berlin) - April 1992

Matthias Wienold, Germany - chair; Marc Regnard; Jonathan Grimshaw, UK

April 1992 (GA election, Berlin) - February 1993

Matthias Wienold, Germany - chair; Jonathan Grimshaw, UK; Stephan Dressler³², Germany

February 1993 (GA election, Berlin) - 19 March 1994

Matthias Wienold, Germany - chair; Robin Gorna, UK; Xavier Rey-Coquais, France

19 March 1994 (GA election, Milan) - 5 November 1994

Hans-Josef Linkens, Germany - chair; Nathalie Dagron, France; Kees Rümke, Netherlands

5 November 1994 (Extraordinary GA (EGA) election, Budapest) - 22 July 1995

Hans-Josef Linkens, Germany - chair; Nathalie Dagron³³, France; Stéphane Korsia, France

22 July 1995 (GA election, Lisbon) - 8 September 1996

Hans-Josef Linkens, Germany - chair; Nathalie Dagron , France; Stéphan Korsia, France

8 September 1996 (GA election Helsinki) - 9 March 1997

Continued: Arjen Broekhuizen, Netherlands - chair; Stefan Mauss, Germany; Raffi Bhabakanian, UK; Francois Houyez, France; Rob Camp, Spain

9 March 1997 (EGA election, London) - 31 August 1997

Arjen Broekhuizen, Netherlands - chair; Stefan Mauss, Germany; Raffi Bhabakanian, UK; Francois Houyez, France; Rob Camp, Spain

31 August 1997 (GA election, Rotterdam) - 25 May 1998

Continued: Arjen Broekhuizen, Netherlands - chair; Rob Camp, Spain; Nico Hollander, Netherlands; François Houyez, France - Secretary; Raffi Babakhanian, UK - Treasurer; Ana Maria Dos Santos De Sousa Passos, Portugal

25 May 1998 (EGA election, Raunheim)-14 June 1998

Arjen Broekhuizen, Netherlands – Chair; François Houyez, France – Secretary; Raffi Babakhanian, UK – Treasurer; Ana Maria Dos Santos De Sousa Passos, Portugal; Rob Camp, Spain; New: Filippo von Schloesser, Italy; Tytti Anneli Poutanen, Finland

³² Co-opted in after death of Marc Regnard

³³ Later replaced by Arnulfo Gonzalez Sanchez

14 June 1998 (GA election, Lisbon) - 30 May 1999

Ana Sousa Passos, Portugal – Chair; Rob Camp, Spain – Secretary; Filippo von Schloesser, Italy – Treasurer; Arjen Broekhuizen, Netherlands – Vice Chair; François Houyez, France

30 May 1999 (GA election, Roissy) - 20 May 2000

Ana Sousa Passos, Portugal – Chair; Rob Camp, Spain – Secretary; Filippo von Schloesser, Italy – Treasurer; Arjen Broekhuizen, Netherlands – Vice Chair; François Houyez, France

20 May 2000 (GA election, Athens) - 6 May 2001

Filippo von Schloesser, Italy – Chair; Rob Camp, Spain – Secretary; Jorma Koskinen, Finland – Treasurer; Katy De Clercq, Belgium; Nikos Dedes, Greece; François Houyez, France

6 May 2001 (GA election, Brussels) - 26 May 2002

Filippo von Schloesser, Italy – Chair; Alain Volny-Anne, France – Secretary; Jens Wilhelmsborg, Denmark – Treasurer; Mauro Guarinieri, Italy; Katy De Clercq, Belgium

26 May 2002 (GA election, Bologna) - 17 May 2003

Filippo von Schloesser, Italy – Chair; Alain Volny-Anne, France – Secretary; Jens Wilhelmsborg, Denmark – Treasurer; Mauro Guarinieri, Italy

17 May 2003 (GA election, Budapest) - 7 June 2004

Mauro Guarinieri, Italy - Chair; Kevin Moody, Netherlands – Secretary; Jens Wilhelmsborg, Denmark – Treasurer; Maxime Journiac, France – Vice Chair

7 June 2004 (GA election, Berlin) - 21 May 2005

Mauro Guarinieri, Italy – Chair; Kevin Moody, Netherlands – Secretary; Jens Wilhelmsborg, Denmark – Treasurer; Wim Vandeveldé, Portugal; Maxime Journiac, France

21 May 2005 (GA election, Madrid) - 13 May 2006

Nikos Dedes, Greece – Chair, Smiljka Malesevic (nee Malesevic), Serbia - Secretary, Wim Vandeveldé, Portugal - Treasurer; Alain Volny-Anne, Secretary, France

13 May 2006 (GA election, Prague) - 24 September 2006

Remaining: Nikos Dedes, Greece – Chair, Smiljka Malesevic, Serbia - Secretary, Wim Vandeveldé, Portugal – Treasurer

Elected: Koen Block, Belgium; Luis Mendão, Portugal

24 September 2006 (EGA election, Madrid) - 6 May 2007

Continued: Nikos Dedes, Greece – Chair, Smiljka Malesevic, Serbia - Secretary, Wim Vandeveldé, Portugal – Treasurer; Koen Block, Belgium; Luis Mendão, Portugal

6 May 2007 (GA election, Stockholm) - 25 May 2008

Continued: Wim Vandevelde, Portugal - Chair; Koen Block - Belgium - Treasurer; Alain Volny-Anne, France - Secretary; Smiljka de Lussigny, Serbia

25 May 2008 (GA election, Vienna) - 22 May 2009

Wim Vandevelde, Portugal - Chair; Stefan Stojanovik, Macedonia - Treasurer; Alain Volny-Anne, France - Secretary; Smiljka de Lussigny, Serbia³⁴; Thandi Haruperi, UK

22 May 2009 (GA election, Brussels) - 30 May 2010

Anna Akowicz, Lithuania - Chair; Stefan Stojanovik, Macedonia - Treasurer; Alain Volny-Anne, France - Secretary; Luis Mendão, Portugal - Vice Chair

30 May 2010 (GA election, Frankfurt) - 11 September 2011

Anna Akowicz, Lithuania - Chair; David Haerry, Switzerland - Secretary³⁵; Stefan Stojanovik, Macedonia - Treasurer; Luis Mendão, Portugal - Vice-chair; Alain Volny-Anne, France; Ferenc Bagyinszky, Hungary³⁶

11 September 2011 (GA election, Berlin) - 23 September 2012

Ferenc Bagyinszky, Hungary - Chair; Stefan Stojanovik, Macedonia - Treasurer; Brian West, UK - Secretary

23 September 2012 (GA election, Berlin) - 14 September 2013

Brian West, UK -Chair, Tomislav Vurušić, Croatia -Treasurer; Ferenc Bagyinszky, Hungary-Vice chair; Tamas Bereczky, Hungary - Secretary; Anna akowicz, Denmark

14 September 2013 (GA election Šibenik) - 20 September 2014

Continued: Brian West, UK -Chair; Tomislav Vurušić, Croatia -Treasurer; Ferenc Bagyinszky, Hungary-Vice chair; Tamas Bereczky, Hungary - Secretary; Olimpi Hoxhaj, Albania

20 September 2014 (GA election Istanbul) - 26 September 2015

Brian West, UK -Chair; Tamas Bereczky, Hungary - Secretary; Tomislav Vurušić, Croatia -Treasurer; Luis Mendão, Portugal - Vice Chair

26 September 2015 (GA election Sesimbra) - 24 September 2016

Luis Mendão, Portugal -Chair, Tomislav Vurušić, Croatia -Treasurer, Sanja Belak Kovacevic, Croatia -Secretary; Jackie Morton, UK; Nikos Dedes, Greece

24 September 2016 (GA election Sofia) - 23 September 2017

Jackie Morton -Chair, UK; Sanja Belak Skugor, Croatia - Secretary; Brian West, UK -Treasurer; Luis Mendão, Portugal; Nikos Dedes, Greece

³⁴ Left the BOD prior to GA as by that time she had become the acting Executive Director

³⁵ Resigned as of May 1st, 2011

³⁶ Became secretary starting from May 1st, 2011



Respondents and commentators for this publication

The following people kindly shared their views and opinions for this document (EATG positions are as at 2017):

- EATG Membership, via an online survey in May 2017
- Christina Antoniadi (UK/Greece) - EATG Member, Women's Group Coordinator
- Giorgio Barbareschi (Belgium) - EATG Staff (Science Officer)
- Tamás Bereczky (Hungary) - EATG Member and Communications Officer
- Gus Cairns (UK) - EATG Member, formerly Prevention Coordinator
- Mario Cascio (Italy) - EATG Member
- Ben Collins (UK) - EATG Member
- Giulio Corbelli (Italy) - EATG Member, and ECAB Chair
- Anna Dovbakh (Latvia) - formerly Eurasian Harm Reduction Network (EHRN)
- Kevin Fisher (US) - AVAC (Global Advocacy for HIV Prevention)
- Damian Kelly (UK) - EATG Member, Training and Capacity Building Chair
- Michael Krone (Germany) - AIDS Action Europe
- Kristjan Jachnowitsch (Germany) - EATG Staff (Training Coordinator)
- Maxime Journiac (France) - EATG Member
- Evgenia Maron (France) - EATG Member, and TB Coordinator
- Luis Mendao (Portugal) - EATG Board Member
- Henning Mikkelsen (Denmark) - formerly UNAIDS
- Jackie Morton (UK) - EATG Member and BoD Chair
- Sini Pasanen (Finland) - Positiiviset Ry, HIV Finland
- Ioan Petre (Romania) - EATG Member
- Juergen Rockstroh (Germany) - University of Bonn
- Shona Schonning (US) - EATG Member
- Andrej Senih (Macedonia) - EATG Member, Policy Working Group Chair
- Raminta Stuikyte (Lithuania) - EATG Member
- Ann-Isabelle Van Lingen (Belgium) - EATG Staff (Policy Officer)
- Brian West (UK) - EATG Board Member
- Mariana Vicente (Belgium) - EATG Staff (Project Manager)

EATG wants to explicitly thank its current and previous members, staff, partners and stakeholders. Without their continued support and collaboration many of the achievements would not have been realised. Special thanks also goes to the board and the members of the External Advisory Board.

