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European
AIDS Treatment
Group

twenty years of treatment activism

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This publication was prepared by Misha Hoekstra and Jeffrey V. Lazarus with the generous assistance of Koen Block. Many past and current EATG members also contributed to this publication. Particular thanks goes to all those whose interviews appear in the pages that follow as well as many others who commented on particular aspects of the publication. We, the authors, dedicate this book to all activists fighting for access to HIV treatment not just in Europe but around the world, and in particular to those who have fallen because of a lack of access.

Design: inextremis.be

Photo credits: EATG archives; Josh Gross (joshuatree.dk), for photos from the HIV in Europe Copenhagen 2012 conference; Matthias Wienold.


H.I.V.
SITIVE
SIND UNSCHULDI

HISTORY

> "It's like we're quibbling over the choice on the menu in the West, while 95% of the world can't even get into the restaurant."
>
> *—Robert Munk on antiretroviral treatment, Glasgow 2004*

THE EARLY YEARS (1991–1995)

AIDS & Medication – founding – early conferences

In March 1991, the Terrence Higgins Trust (THT) in London contacted Deutsche AIDS-Hilfe (DAH) about holding a seminar in six weeks' time, as part of a series sponsored by the European Commission and offered by various HIV service organisations across the European Union. Since DAH was the only organisation that had any staff working specifically with treatment, THT asked it to organise a seminar on AIDS and medicine, which would become the first AIDS & Medication meeting.

The head of DAH's department of medicine and health policy, Matthias Wienold, considered offering an expanded version of the organisation's treatment information sessions. Instead, after consulting with Nick Partridge (THT), Robin Gorna (European Commission), and two German activist friends, Andreas Salmen and Jürgen Poppinger, he decided on what he termed "a much more selfish" focus: treatment activism. Selfish, Wienold said, because he hardly knew anyone who shared the interest, while also believing at the same time that it might help bring reform to a deeply flawed system.

In the end, about a dozen activists attended, representing Germany, the United Kingdom, and three other European countries, Gathering for two days in May 1991, they discussed what treatment activism, which had previously been primarily an American phenomenon, might look like in a European setting. In the wake of a difficult struggle with Bristol-Myers over ddI, the participants were excited about the prospect of combining forces. They identified three areas requiring action: access to treatment, standards of ethical conduct, and treatment education and information.

By the time the VII International AIDS Conference took place in Florence the next month, the participants had drafted the European AIDS Treatment Agenda, which brought a European perspective to bear on the treatment agenda developed by ACT UP New York. They hoped that this agenda would serve as a rallying cry for the group and a basis for interactions with the pharmaceutical industry.

Other people gradually became involved, and the participants began developing project ideas, including what became the European AIDS Trials Directory and the European Community Advisory Board (ECAB). Wienold also proposed a newsletter, *European AIDS Treatment News* (*EATN*), and a second meeting.

The 2nd AIDS & Medication meeting convened in Berlin on 23 February 1992. The participating activists formally inaugurated themselves as the European AIDS Treatment Group, with 19 members from nine EC countries[1] and Switzerland, as well as observers from the European Commission and WHO Europe. The proposed constitution was passed unanimously, limiting membership to indi-

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

viduals, with annual dues of 2 German marks (about €1).

The EATG's founding members also drafted a budget and elected a board, consisting of Jonathan Grimshaw, Marc Regnard and Matthias Wienold. Regnard died shortly after the meeting, however, and was succeeded by Stephan Dressler. Wienold served as the first executive director, a post he held for three years, and continued to edit *EATN* as well. Meanwhile, DAH agreed to host the secretariat and provide the organisation with a home base, although it was hardly a proper office.

In a membership appeal printed later that year in the *EuroCASO Newsletter*, Wienold explained why the EATG had been founded, stating, "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 that the EATG had identified for itself: 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 Spring 1993, the group had grown to 30 members representing 14 countries, almost entirely in western and northern Europe[2]. The AIDS & Medication meeting and the EATG General Assembly (GA) that followed directly on its heels were particularly exhausting for participants that year, exacerbated by language difficulties, hardball questions for company representatives, frustration with European regulators, and often intense internal discussions. But the fact that treatment activists were finally collaborating across national borders and engaging the industry and regulatory agencies showed that the EATG was solidly established and already making its voice heard.

The growing organisation formed its own secretariat in 1994 and opened a bank account. It presented its work at the X International AIDS Conference in Yokohama. Ian Weller also invited the EATG to address the International Congress on Drug Therapy in HIV, held in Glasgow, and Matthias Wienold spoke at the closing plenary. The group's collaboration with the Glasgow conference is still going strong today.

The EATG was also represented at two other important conferences early in the following year: the HIV Infection in Women Conference (Washington, DC) and the 6th International Conference on the Reduction of Drug Related Harm (Florence).

In mid-1995, the *EATN* started to be available electronically through HIVnet, which ran on Fidonet, an alternative to the World Wide Web. Users could dial up modems in Amsterdam, Barcelona, Berlin, London and Paris, accessing the *EATN* by using the FidoNet address

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

2:280.413. At this point, some 650 hard copies of each issue of the *EATN* were being distributed free of charge throughout Europe. Within a year there were 1000 subscribers, including 120 libraries, enabling the editors to say it was “probably the most widely read treatment information newsletter in Europe”. The *EATN* was largely supported during this period by grants from Hoffmann-La Roche on the condition of editorial independence – a condition reflected in the fact that the firm was criticised openly and frequently in the newsletter pages.

STATEMENT OF PURPOSE

❶ The EATG contributes to the public health and welfare system by:
  - [providing] information and counselling on the Aquired Immuno Deficiency Syndrome (AIDS) and clinical, medical and social issues related to it;
  - striving to achieve effective treatment and access to experimental therapies for as many people with HIV/AIDS as possible as soon as possible;
  - striving to enable people with HIV/AIDS to maximum control over the treatment and research agenda;
  - supporting institutions and organisations aiming to achieve identical goals;
  - networking of European initiatives and self-help groups that are contribute[ing] to the same aims.

❷ The EATG promotes unprejudiced presentation of AIDS-related issues in public and aims to improve the well-being of people with HIV/AIDS in societies.

❸ The EATG is politically and confessionally [i.e. religiously] independent.

Source: EATG Board of Directors. *Constitution of the “European AIDS Treatment Group”*. Berlin, 24 February 1992.

YEARS OF GROWTH (1996–1999)

Expanding south – ECAB – the start of lobbying

The EATG started a dialogue with the European Medicines Agency (EMEA, later EMA) in 1996. After participating in the historic XI International AIDS Conference in Vancouver, at which the efficacy of combination therapy with protease inhibitors was first reported, the group considered starting to lobby at the European level in order to ensure access to the new lifesaving treatments. It also discussed for the first time the idea of holding training sessions in southern Europe to educate new activists and increase community engagement there.

The year 1997 became a historic one for the EATG in the spring when it organised its first European Community Advisory Board (ECAB) meeting. In the early 1990s, when the EATG was founded, CABs in Europe existed as company-associated entities. At the 1994 AIDS & Medication meeting, EATG members had confirmed an earlier decision not to represent individual constituencies, adopting instead an activist approach to clinical research and science based on a broader sense of community that embraced all affected groups throughout Europe. Now, the organisation established ECAB independent of individual pharmaceutical companies. Its composition was to be decided upon by the EATG, and it was to be accountable to the EATG and the community. It took several years of work and experience to establish the ECAB model now used, but its simultaneous independence of and engagement with pharma continue unbroken from the beginning to the present day.

As more effective treatments became available, problems with adherence also began to emerge. The EATG developed a 30-minute English-language video called *Moments of Decision*, addressing compliance. Translations into French, Italian, Portuguese and Spanish followed, and the videos were distributed by community groups and health providers throughout Europe.

Following the success of this initiative, the EATG decided to organise a standard-of-care meeting and develop a European standard-of-care protocol, which was followed the next year by the first meeting of the Standard of Care Working Group. The EATG also organised the First International Symposium on Compliance with HIV Therapy, which it held in conjunction with the 1997 GA in Rotterdam. This symposium was attended by a diverse group of 225 health care workers, pharma representatives, treatment activists and journalists.

That summer, the EATG also arranged its first training course for treatment activists in southern Europe, in Barcelona, attended by roughly 100 delegates – primarily new treatment activists – from countries including Belgium, France, Greece, Italy, Portugal, Spain, Turkey and the United Kingdom.

The year 1997 was also the start of the Lobbying Working Group (LWG). With its formation, the 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, entering into dialogue with DGs that were then known as III (Industry), V (Health and HIV), XII (Science and Research) and XXIV (Consumer Affairs).

By 1997 the organisation had grown to become a network of over 100 AIDS treatment activists from 17 countries. Along with the expansion in the nature of its activities – the ECAB, EU lobbying, the compliance video, the standard-of-care protocol and activist training – it seemed high time for the EATG to move into its own office. In June, it accordingly moved from the DAH office in Berlin to new quarters in Düsseldorf. The BoD had its geographical focus west of Berlin and the move served to ease communication and disentangle the work from DAH. At the same time, through the help of volunteers and new employees, it was able to organise its rather chaotic files and institute some regular bookkeeping procedures.

As the membership continued to grow, the need for a different organisational structure became apparent. The membership rolls were brought up to date, and in October 1998 Peter Scott, one of the founding members, presented a first draft of a membership handbook to the GA. He also presented initial suggestions from a comprehensive organisational review he had been conducting, identifying problems, obstacles and opportunities. The GA adopted the bulk of his suggestions, including staff job descriptions, an ombudsperson, new working groups, an electronic office and protocols for elections, GAs, budgeting and events.

The EATG also obtained funding that allowed it to act on a long-held wish to make key publications available in languages other than English. Thanks to EU support, the *EATN* began appearing in four languages in addition to English (French, Italian, Portuguese and Spanish). In addition, the organisation launched the Continuous Patient Education Project (COPE) in 1998 to translate various educational materials, although the project would not really get up and running until 2000.

In 1999, the EATG purchased the web domain that it still uses today, www.eatg.org. The group continued its seminars in southern Europe, and it expanded east for the first time, with its first training event for treatment activists in central and eastern Europe, a one-day seminar at the Global Network of People Living with HIV/AIDS (GNP+) conference in Warsaw in August.

Meanwhile, the Standard of Care Working Group working group was merged into the European Guidelines Group (EGG), which was designed to promote equality of care throughout Europe. In April, this group coordinated a meeting of 25 virologists, physicians and diagnostic company representatives in Brussels to discuss diagnostic developments in HIV care, particularly in the area of resistance testing, with the aim of developing guidelines and promoting equal access to these resources for people living with HIV.

THE EATG ENTERS THE NEW MILLENNIUM (2000–2005)

Expanding east – research & prevention – Brussels

Reflecting its increased attention to training activities, the EATG organised the Trainers' Working Group in 2000, which started the new millennium by sponsoring training conferences in central and eastern Europe. After the success of the seminar in Warsaw the previous year, the group organised a second training seminar for activists from these regions in April, in Budapest, attended by 45 members of national NGOs. A third seminar followed at the end of September, 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.

At the same time, COPE began working with local NGOs from that part of Europe to translate educational materials into various languages, starting with a leaflet on combination therapy. Between 2001 and 2006, COPE would fund 27 translation projects. With the exception of one Italian translation, all of these projects targeted central and eastern Europe.

Meanwhile, the Lobbying Working Group was interfacing more and more with both the European Commission and the European Parliament, culminating in an EATG-hosted meeting at Parliament on 24 May 2000, at which the EATG explained its vision for the role of HIV organisations and the need for prioritising the HIV pandemic on the EU health policy agenda. The following year, the GA met in Brussels and started weighing a move to the city to increase the effectiveness of its EU lobbying activities.

The 2001 GA also approved a revised Membership Handbook by unanimous vote. The handbook consisted of a detailed series of protocols detailing EATG procedures and member roles and responsibilities. Following a recommendation from the previous GA, the organisation also instituted a Declaration of Interest (DOI) for all members, requiring them to identify potential conflicts of interest.

The Access Working Group was established to focus on increasing access to treatment in eastern Europe and developing nations. Access was also an important internal issue for the EATG; results from a focus group concluded that representation and diversity should be a key goal within the organisation, since major groups of HIV-positive individuals were underrepresented in the EATG

– including people of colour, migrants, people who inject drugs, women, heterosexual men, parents of HIV-positive children, young people, sex workers and eastern Europeans.

In 2002, a Vaccines Working Group (VWG) was established, and the Lobbying Working Group changed its name to the more innocuous-sounding Policy Working Group (PWG).

In 2003, the EATG decided to define its geographic focus in its mission statement as the entire WHO European Region, comprising 53 member states. In doing so, the organisation explicitly committed itself to addressing treatment issues connected with the world's fastest growing epidemic, then taking place in eastern Europe and central Asia.

This expanded focus led to the 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 in Kiev, the seminar was attended by 80 participants and featured an ECAB meeting dedicated to HIV issues in the region, which enabled local advocates to meet with pharma representatives and air their concerns about access and pricing.

Another ECAB meeting during the same year was devoted to the theme of vaccines. This meeting included a training session on basic vaccine immunology, a survey of the HIV vaccine development pipeline and a discussion of the gender implications of clinical trial designs for vaccines. The meeting formed the basis for a booklet that the group published two years later. In October, the EATG presented a poster at the 9th European AIDS Conference in Warsaw, summarising information in the European Therapeutic Vaccine Trials Database.

The year 2003 also saw the EATG engaging several major UN bodies for the first time. In September, it played a key role in developing the joint statement released by all the NGOs present at the World Trade Organization's Fifth Ministerial Conference, in Cancun. It was also involved in most of the formal motions and outside demonstrations organised during the meeting. In addition, EATG representatives participated in a high-level meeting devoted to the 3 by 5 Initiative, arranged in Geneva by WHO, the Global Fund and UNAIDS.

After a period of inactivity, the Policy Working Group reconstituted itself in February 2004. The EATG was selected to represent civil society in the drafting panel of the Dublin Declaration that month and was successful in influencing the final statement; PWG also contributed substantively to the Vilnius Declaration later in the year.

During this time, the EATG strengthened its links with other advocacy organisations, with harm reduction and drug users' groups from both eastern and western Europe, and with networks of people living with HIV. These organisations included 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 GNP+.

Finally, the year 2004 brought two major shifts in EATG focus. First, in May and June. after several years of discussion and exploration, it finally closed its Düsseldorf office and moved to Brussels so that it could lobby EU bodies more effectively. Highlights of its involvement in EU activities during the year included participating in a June ministerial meeting organised by Ireland when it held the EU Presidency, and joining the new HIV/AIDS Think Tank set up by the DG for Health and Consumer Protection (DG Sanco).

Second, during the GA held in Berlin June, the organisation committed itself to becoming outcome-oriented by starting to allocate the bulk of its resources to specific projects that had measurable outcomes, rather than to simple structural funds for working groups.

ADOLESCENT YEARS (2005–2009)

Further eastward – strategy – coinfections – vulnerable populations

At a meeting with DG Sanco in May 2005, the EATG and AIDS Action Europe agreed to organise a consultation with NGOs on the EU's new approach to HIV in its member states and neighbouring countries. One of the meeting's chief outcomes 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 (p. 44). Although the EATG and AIDS Action Europe initially served as observers to the forum, they were subsequently elevated to the position of co-chairs.

In order to embrace new avenues of development, the Vaccine Working Group became the New Preventive Technologies Working Group. It collaborated with the brand new Eastern States Working Group to sponsor a training workshop on HIV vaccine clinical trials in eastern Europe in October. The new technologies group also worked with ECAB to organise an ECAB meeting on microbicides in December.

In 2005, the Eastern States Working Group had 29 members (including both EATG members and non-members), from Belarus, Bulgaria, Estonia, Georgia, Italy, Macedonia, Moldova, the Russian Federation, Serbia, Ukraine and the United Kingdom. Reflecting the organisation's greater attention to eastern Europe, the *EATN* was translated into Russian for the first time.

Yet the *EATN*'s days were numbered, and only two issues appeared in 2005 and one in 2006 before publication was suspended indefinitely. Factors involved in the decision to discontinue the *EATN* included high production costs for what had now become a glossy magazine, as well as a lack of clarity about the target audience, with some people lamenting the technical difficulty of the articles and others praising it. In addition, while in the early days the *EATN* provided critical information not readily available anywhere else, the rise of the Internet now provided immediate access to a wealth of current treatment information.

Ambition was not lacking in other parts of the organisation, however. During 2006, the EATG developed its first long-term strategy, covering the next four years. A simplification of the organisational structure left the organisation with just three working Group – PWG, ECAB and the Development and Membership Working group – and two task forces (Eastern States and Capacity-Building). PWG now covered a broad swath of interests, and by June 2007 it could boast 17 portfolios:

- access to treatment and care
- pricing, scaling up and pharmacoeconomics
- free trade agreements, trade policies and intellectual property issues
- mortality and morbidity surveillance, AIDS and mortality
- sexual and reproductive rights and health
- research and community
- drug safety and patient safety
- positive prevention
- human rights, stigma, travel restrictions and criminalisation
- patient information and health literacy
- new preventive technologies

- drug users
- prisoners
- migrants and ethnic minorities
- southeast, central and eastern Europe
- women
- men who have sex with men.

The increased level of policy activity led the organisation to hire a policy officer in 2007.

The EATG organised several sessions reflecting its new interests in 2006, including a community forum on entry and travel regulations at the XVI International AIDS Conference in Toronto. Furthermore, it organised a seminar at the Glasgow conference on the criminalisation of HIV transmission, including the implications for clinical services, confidentiality and doctor-patient relations. This seminar paved the way for the EATG's involvement the following year in a UNDP and UNAIDS consultation on the criminalisation of HIV transmission.

In 2007, the EATG cosponsored the first annual Sitges symposium, on drug development for HIV and hepatitis C coinfection, with a local NGO. This multi-stakeholder meeting resulted in the first Sitges Statement, a joint declaration by HIV and hepatitis C activists, doctors, researchers, and representatives from pharmaceutical companies and regulatory agencies. This initial statement focused on the research agenda and on access to experimental hepatitis C drugs for people living with HIV. The EATG continues to organise this symposium every year.

In June, the EATG and a local NGO organised a conference in Lisbon on migrants' and ethnic minorities' right to HIV services, attended by 230 community participants from throughout the European Region. The conference 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 the EATG in 2008.

Meanwhile, the EATG became involved in two research projects funded by the EU: the similarly titled European AIDS Treatment Network (NEAT) and the European Vaccines and Microbicides Enterprise (EUROPRISE) consortium, both of which were funded to run from 2007 through 2012.

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

The EATG helped WHO Europe to initiate and oversee the drafting and publication of the first progress report on the Dublin Declaration (p. 44). This report assessed how well the countries of the European Region were making good on all the actions they committed to in 2004. Published in 2008, the report not only provided a 300-page snapshot on the state of the European epidemic and efforts to address it, but it also gave countries and organisations a roadmap of what they needed to do next. The 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 March 2008, the 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 – to focus advocacy work on pharmaceutical procurement and supply issues that were limiting access to treatment in the region. The workshop followed on the heels of an EATG collaboration with a Correlation Network conference in Sofia on social inclusion and health, which sought to link a variety of initiatives in order to improve access to services for marginalised groups.

In its role as the advocacy secretariat of the HIV in Europe Initiative, the EATG organised 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.

The same month, the EATG organised a satellite community session in Glasgow, entitled “Can HAART prevent HIV transmission?”, that produced a diverse mix of views on the Swiss Federal AIDS Commission’s controversial assertion that HAART could eliminate transmission. The next year, the EATG 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.

The EATG also renewed its emphasis on trainings 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.

At the same time, the PWG developed policy recommendations within the framework of the Correlation II project (2009–2011), which tackled health inequalities in Europe. And the EATG became more involved in the AIDS & Mobility project by developing an innovative health education model for migrants and ethnic minorities.

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 coinfected with HIV, and targeting stigmatised groups and the countries of eastern Europe and central Asia.

By August 2009, when the organisation tapped long-time member Koen Block to be its new executive director, the EATG office had seven other staff members, including a financial manager, a financial projects coordinator, a policy advisor, a scientific advisor and a program assistant who would later become training coordinator.

THE EATG TODAY (2010–2012)

Collaboration – access – hepatitis C – low prevalence

In 2010, ECAB organised a meeting focusing on the clinical aspects of TB and clinical research on TB/HIV coinfection, 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 also began collaborating specifically with the Russian CAB during the year, advising them and sending representatives to their meetings.

As the community partner in the EUROPRISE consortium, the EATG organised a multi-stakeholder community meeting on pre-exposure prophylaxis (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.

As it activities continued to increase in central and eastern Europe, the EATG organised three trainings there 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.

The EATG also developed manuals on treatment literacy and treatment advocacy within the framework of its trainings. Both manuals were translated into Russian.

In 2011, the PWG organised its first five policy dialogue meetings, starting with one 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 of low-prevalence countries in central and south-east Europe delineated in the Budapest Declaration, and a meeting in Bucharest. The other 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.

The EATG launched and distributed the AIDS & Mobility Master Toolkit, a collection of core training materials from the latest incarnation of the project, as well as other relevant information from the fields of HIV prevention and migrant health that the project partners considered essential resources for anyone interested in implementing a transcultural HIV mediator project.

As of 2012, the European AIDS Treatment Group has 109 members from 37 countries. In addition to its recent involvement in the European Patients' Academy on Therapeutic Innovation (EUPATI) project, which addresses community involvement in scientific research and development, the EATG has decided to focus more on coinfections, especially hepatitis C.

MILESTONES

> “If the cure for AIDS was one clean glass of water, most people in the world today would not have access to treatment.”
>
> —*Josef Decostas, quoted in the* EATN *after the Vancouver conference, July 1996*

MILESTONES IN UNIVERSAL ACCESS to HIV prevention, treatment and care

- Under the guidance of Peter Piot, UNAIDS launches the Drug Access Initiative
- First introduction of antiretroviral therapy in sub-Saharan Africa

- XII International AIDS Conference in Geneva addresses gap in treatment between wealthy and poor, gap in power and autonomy between men and women, and gap between government authorities and civil society. The Geneva principle is established to provide a balance between community and scientific concerns in the conference program
- Treatment Action Campaign (TAC) is founded and starts activity in South Africa

- Launch of the Brazilian AIDS Control Program, with local production of antiretrovirals
- Launch of the Accelerating Access Initiative by UNAIDS, WHO, the World Bank, UNICEF, UNPF and the pharmaceutical industry to decrease antiretroviral prices

- Launch of WHO prequalification program for generic antiretrovirals.
- Durban AIDS Conference focuses world attention on the continent most affected by HIV and inspires world-wide movement for treatment access. The conference proves to be a unique opportunity to address both treatment inequity and denialism
- Signed by 197 countries, the UN Millennium Declaration establishes eight global development goals, including one devoted to HIV that focuses on providing universal treatment access by 2010 and reversing the spread of HIV by 2015
- Agreement on tiered drug prices between the EU, ACT UP, Médecins Sans Frontières, generic manufacturers, pharmaceutical companies, WHO and UNAIDS

- African Summit on HIV/AIDS in Abuja, Nigeria
- UN General Assembly Special Session on AIDS (UNGASS) passes the Declaration of Commitment to scale up a comprehensive response to HIV that involves prevention, treatment, care and support
- Kofi Annan proposes the creation of a global fund to fight HIV, TB and malaria

- WHO publishes its first HIV treatment guidelines: *Scaling up Antiretroviral Therapy in Resource-Limited Settings*
- WHO adds 10 antiretrovirals to its List of Essential Medicines
- The Global Fund to Fight AIDS, Tuberculosis and Malaria meets for the first time, and community involvement is high on the agenda

2003

- Creation of PEPFAR (US President's Emergency Plan for AIDS Relief)
- WHO launches the 3 by 5 Initiative, with the worldwide goal of putting 3 million people on ART by 2005

2005

- G8 Gleneagles Summit endorses the goal of providing "as close as possible to universal access to treatment for AIDS by 2010"
- WHO establishes the Global Price Reporting Mechanism, which consolidates information on antiretroviral prices paid by low- and middle-income countries

2007

- The goal of 3 million people on ART is finally reached

2010

- WHO updates its ART guidelines, recommending earlier initiation of treatment
- The Vienna Declaration focuses on the protection of human rights as an essential element of universal access to treatment and care
- UNAIDS and WHO launch Treatment 2.0, a program aimed at dramatically simplifying HIV treatment and care by optimising drug regimens, promoting point-of-care diagnostics and simpler monitoring, and improving service delivery systems

2011

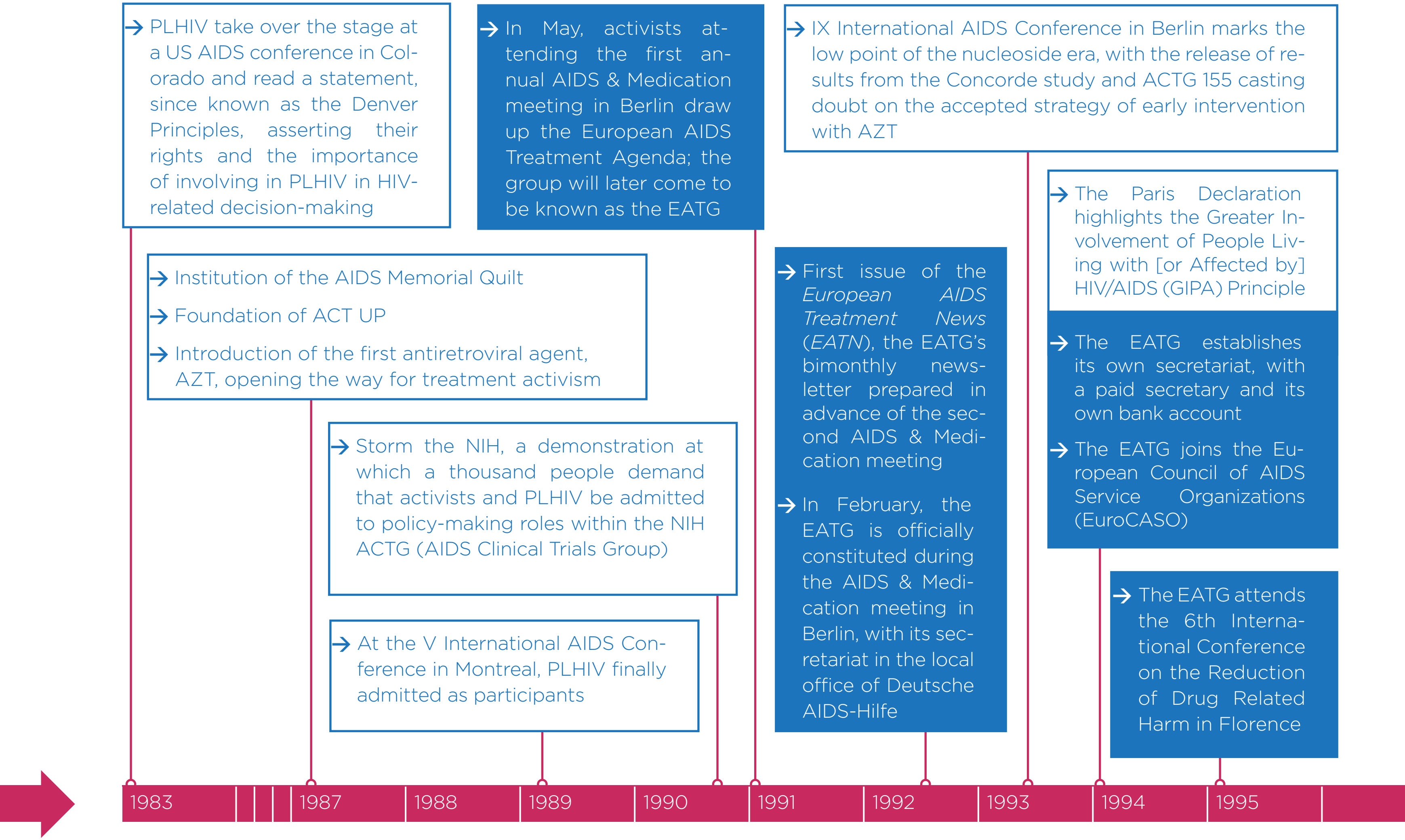
- Seven million people are on ART, funded primarily by the Global Fund and PEPFAR
- Results presented at the IAS Conference in Rome demonstrate that ART significantly reduces HIV transmission, thus making it an important prevention tool
- At a high-level UN meeting on HIV, countries recommit to universal access, with a target of 15 million on treatment by 2015

2012

- The International AIDS Conference returns to the US after the travel ban on people living with HIV is lifted. Some 25,000 participants attend and, together with HIV Europe, the EATG organises the European Networking Zone

Source: Adapted from Vella et al. The history of antiretroviral therapy and of its implementation in resource-limited areas of the world. *AIDS*, 2012, 26:1231–1241.

EATG AND COMMUNITY INVOLVEMENT MILESTONES in the fight against HIV



- PLHIV take over the stage at a US AIDS conference in Colorado and read a statement, since known as the Denver Principles, asserting their rights and the importance of involving in PLHIV in HIV-related decision-making

- In May, activists attending the first annual AIDS & Medication meeting in Berlin draw up the European AIDS Treatment Agenda; the group will later come to be known as the EATG

- IX International AIDS Conference in Berlin marks the low point of the nucleoside era, with the release of results from the Concorde study and ACTG 155 casting doubt on the accepted strategy of early intervention with AZT

- The Paris Declaration highlights the Greater Involvement of People Living with [or Affected by] HIV/AIDS (GIPA) Principle

- The EATG establishes its own secretariat, with a paid secretary and its own bank account
- The EATG joins the European Council of AIDS Service Organizations (EuroCASO)

- Institution of the AIDS Memorial Quilt
- Foundation of ACT UP
- Introduction of the first antiretroviral agent, AZT, opening the way for treatment activism

- First issue of the *European AIDS Treatment News* (*EATN*), the EATG's bimonthly newsletter prepared in advance of the second AIDS & Medication meeting
- In February, the EATG is officially constituted during the AIDS & Medication meeting in Berlin, with its secretariat in the local office of Deutsche AIDS-Hilfe

- Storm the NIH, a demonstration at which a thousand people demand that activists and PLHIV be admitted to policy-making roles within the NIH ACTG (AIDS Clinical Trials Group)

- At the V International AIDS Conference in Montreal, PLHIV finally admitted as participants

- The EATG attends the 6th International Conference on the Reduction of Drug Related Harm in Florence

1996

- Highly active antiretroviral therapy (HAART) introduced at the XII International AIDS Conference in Vancouver

- At the Vancouver conference, the EATG organizes the first international workshop on women in AIDS treatment activism

1997

- European Community Advisory Board (ECAB) founded
- The EATG moves from Berlin to its own office in Düsseldorf
- The EATG organises its first southern states treatment activist training conference in Barcelona

1998

- The EATG adopts new constitution at its June GA
- First draft of the membership handbook
- Creation of the Lobbying Working Group, since "lobbying is integral to the functioning of [the] EATG"

1999

- The EATG organises a one-day seminar for treatment activists at the GNP+ conference in Warsaw, its first for central and eastern European states
- The EATG purchases the web domain **www.eatg.org**
- In August, the EATG is involved in the 9th International Conference for People Living with HIV/AIDS, held in Warsaw, with several sessions devoted to HIV infection and treatment

2000

- The Continuous Patient Education Project (COPE) begins working with local NGOs to translate educational materials into various languages
- Creation of the Trainers' Working Group
- ECAB establishes the XX Study Group in January 2000, focusing on treatment topics particularly relevant to women
- An EATG representative serves on the scientific committee for the 5th International Congress on Drug Therapy in HIV, held in Glasgow in October

2001

- The UN General Assembly endorses the GIPA Principle

- The EATG explores the feasibility of moving to Brussels in order to exert greater influence on EU politics, while maintaining a non-profit presence in Germany

- The Vaccines Working Group (VWG) is established
- Three EATG members serve on the scientific committee for the 6th International Congress on Drug Therapy in HIV in Glasgow, and three members help chair sessions
- The Lobbying Working Group becomes the Policy Working Group

- The EATG is invited to participate on the organising committee for the 1st European HIV Drug Resistance Workshop, held in March in Luxembourg
- The EATG explicitly expands its geographic focus to embrace the entire WHO European Region, including all the countries of the former Soviet Union
- For the first time, EATG representatives meet with WHO at a high-level meeting during a 3 by 5 Initiative meeting in Geneva

- The EATG is elected to represent civil society on the drafting panel of the Dublin Declaration and contributes a number of key points to the final declaration
- In May and June, the EATG closes its Düsseldorf office and moves to Brussels
- The EATG joins DG Sanco's new HIV/AIDS Think Tank
- On World AIDS Day, the Code of Good Practice for NGOs responding to HIV/AIDS is launched with endorsement from more than 160 NGOs

- EATG and AIDS Action Europe organise an NGO consultation for DG Sanco, leading to the first meeting of the Civil Society Forum on HIV/AIDS in September. The EATG becomes co-chair of the forum together with AIDS Action Europe (p. 44)
- The EATG and WHO Europe co-sponsor a technical consultation on collaboration between international public health actors and community-based organisations (p. 48)
- The UN Economic and Social Council grants the EATG special consultative status
- The EATG signs a partnership agreement with UNAIDS on providing training and technical assistance to eastern Europe and central Asia, chiefly through the Strategic Treatment Education Project (STEP)

- The EATG signs a memorandum of understanding with WHO Europe (p. 48)
- The EATG becomes a member of Information to Patients Working Group of DG Enterprise's Pharmaceutical Forum
- EATG develops its first long-term strategy (2007–2010)
- Last issue of the *EATN* published

2002 2003 2004 2005 2006

- → The WHO Regional Office for Europe publishes *HIV/AIDS Treatment and Care: Clinical Protocols for the WHO European Region*, drawing on substantial EATG and community input
- → The EATG begins serving as advocacy secretariat for the new HIV in Europe Initiative, which promotes earlier HIV testing and entry into care
- → The EATG organises Sitges I, the first in a series of annual symposia on drug development for HIV/hepatitis C coinfection, held in Sitges, Spain
- → The EATG organises its biggest conference to date, on migrants and ethnic minorities' right to HIV services, with a local NGO in Lisbon
- → The EATG hosts and updates a database on travel restrictions

- → The EATG organises a roundtable with MEPs and other policy-makers about the need for a comprehensive HIV strategy promoting early diagnosis, reducing testing barriers and ensuring earlier treatment and care, leading to the European Parliament passing a joint resolution on HIV

- → The EATG helps establish an informal cross-party intergroup on HIV issues at the European Parliament
- → On 13 October, the HIV Index, organised by the Health Consumer Powerhouse and the EATG, is launched at the European Parliament
- → ECAB organises thematic meetings on two relatively overlooked topics: the clinical management of lipodystrophy and hepatitis C drug development and access
- → The EATG develops an innovative health education model for migrants and ethnic minorities as part of the AIDS & Mobility project
- → The EATG organises a strategic meeting at the EECAAC meeting in Moscow to define an eastern states strategy not for – but in collaboration with – partners from the region
- → The EATG co-chairs the EMA's Patient & Consumer Working Party
- → The EATG starts an internal newsletter (December 2009)
- → An operational grant allows the EATG to renew its emphasis on trainings, with a focus on central and eastern Europe. A trainers' pool is created within the EATG

2007 2008 2009

- ECAB holds a meeting on the clinical aspects of TB/HIV coinfection
- The EATG starts a new external newsletter (January)
- ECAB starts collaborating with EECA CAB; a thematic ECAB workshop on generic HIV medicines takes place in June in Kiev
- The EATG organises a series of events and presentations at the International AIDS Conference in Vienna
- The EATG organises a multi-stakeholder community meeting on pre-exposure prophylaxis (PrEP) research and development priorities for the EUROPRISE consortium
- The EATG organises trainings on HIV treatment literacy and advocacy in partnership with PLHIV networks in Estonia and Ukraine

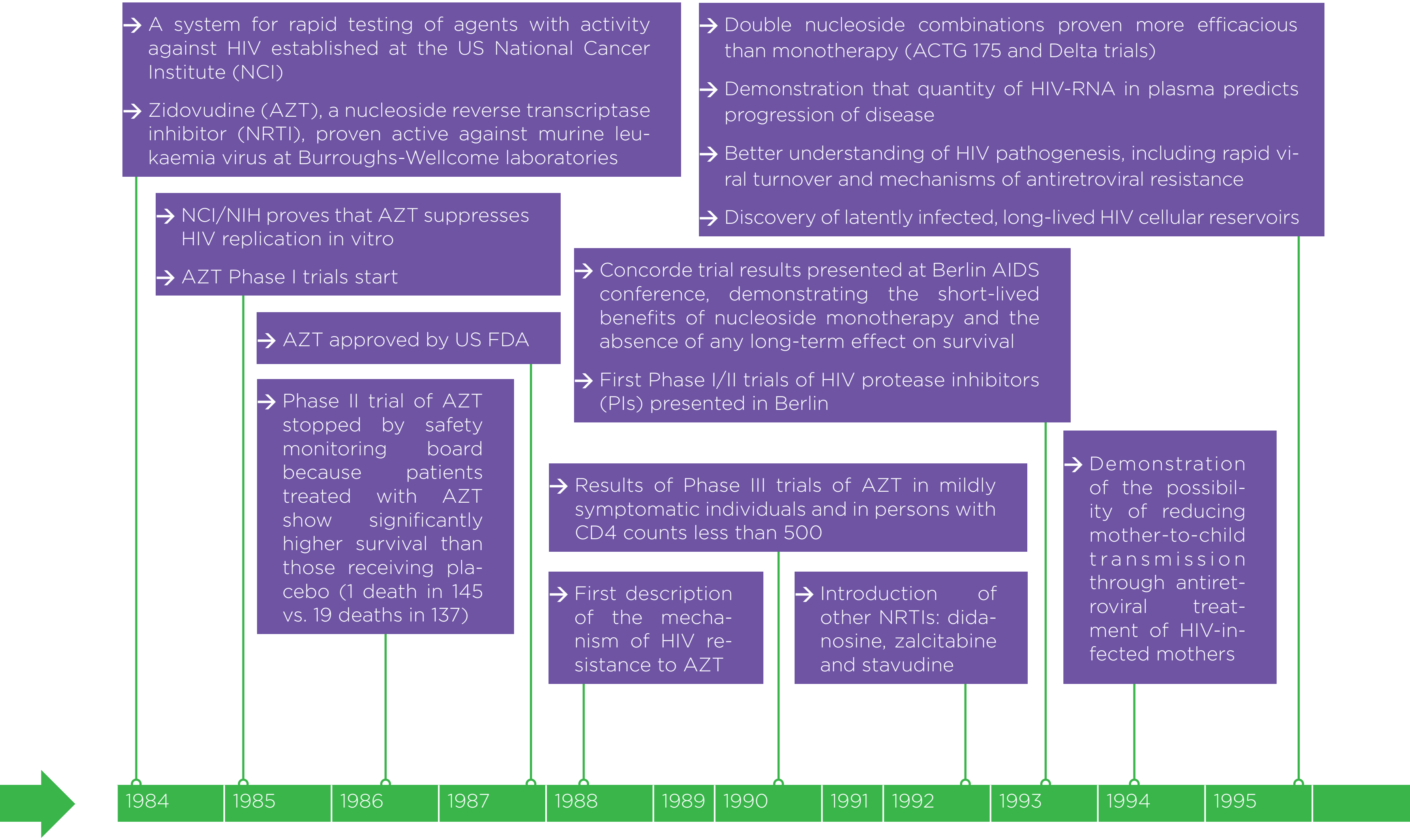
- The EATG organises five policy dialogue meetings, in Riga, Budapest (on HIV in low-prevalence countries), Belgrade (on the Budapest Declaration), Brussels and Bucharest
- The EATG organises a policy dialogue meeting to discuss the Correlation II draft policy recommendations on HIV, challenge policy-makers to address the priorities identified and engage HIV and harm-reduction community members in joint advocacy activities
- The EATG launches and distributes the AIDS & Mobility Master Toolkit, a collection of training materials on HIV prevention and migrant health
- The EATG organises a community session on treating migrant patients at the 10th International Congress on Drug Therapy in HIV Infection, in Glasgow
- The EATG creates its second long-term strategy (2012–2015)

- The HIV in Europe Copenhagen 2012 Conference highlights the importance of community testing and the expanded use of indicator diseases that should prompt HIV testing in health care settings
- The EATG creates a workplan on hepatitis C
- The EATG co-organises the European Networking Zone at the International AIDS Conference in Washington
- The EATG organises a criminalisation seminar in collaboration with Deutsche AIDS Hilfe (DAH), the International Planned Parenthood Federation (IPPF) and the HIV in Europe Initiative
- The EATG celebrates its 20th anniversary in Berlin, where it all began. A new logo and visual identity are introduced

2010
2011
2012


WITH A
ROBIN HOOD TAX
ON WALL STREET
IT'S
TIME
FOR
BANKS
TO
PAY UP.
PLUS

MILESTONES IN THE DEVELOPMENT of antiretroviral therapy



- → A system for rapid testing of agents with activity against HIV established at the US National Cancer Institute (NCI)
- → Zidovudine (AZT), a nucleoside reverse transcriptase inhibitor (NRTI), proven active against murine leukaemia virus at Burroughs-Wellcome laboratories

- → NCI/NIH proves that AZT suppresses HIV replication in vitro
- → AZT Phase I trials start

- → AZT approved by US FDA

- → Phase II trial of AZT stopped by safety monitoring board because patients treated with AZT show significantly higher survival than those receiving placebo (1 death in 145 vs. 19 deaths in 137)

- → Double nucleoside combinations proven more efficacious than monotherapy (ACTG 175 and Delta trials)
- → Demonstration that quantity of HIV-RNA in plasma predicts progression of disease
- → Better understanding of HIV pathogenesis, including rapid viral turnover and mechanisms of antiretroviral resistance
- → Discovery of latently infected, long-lived HIV cellular reservoirs

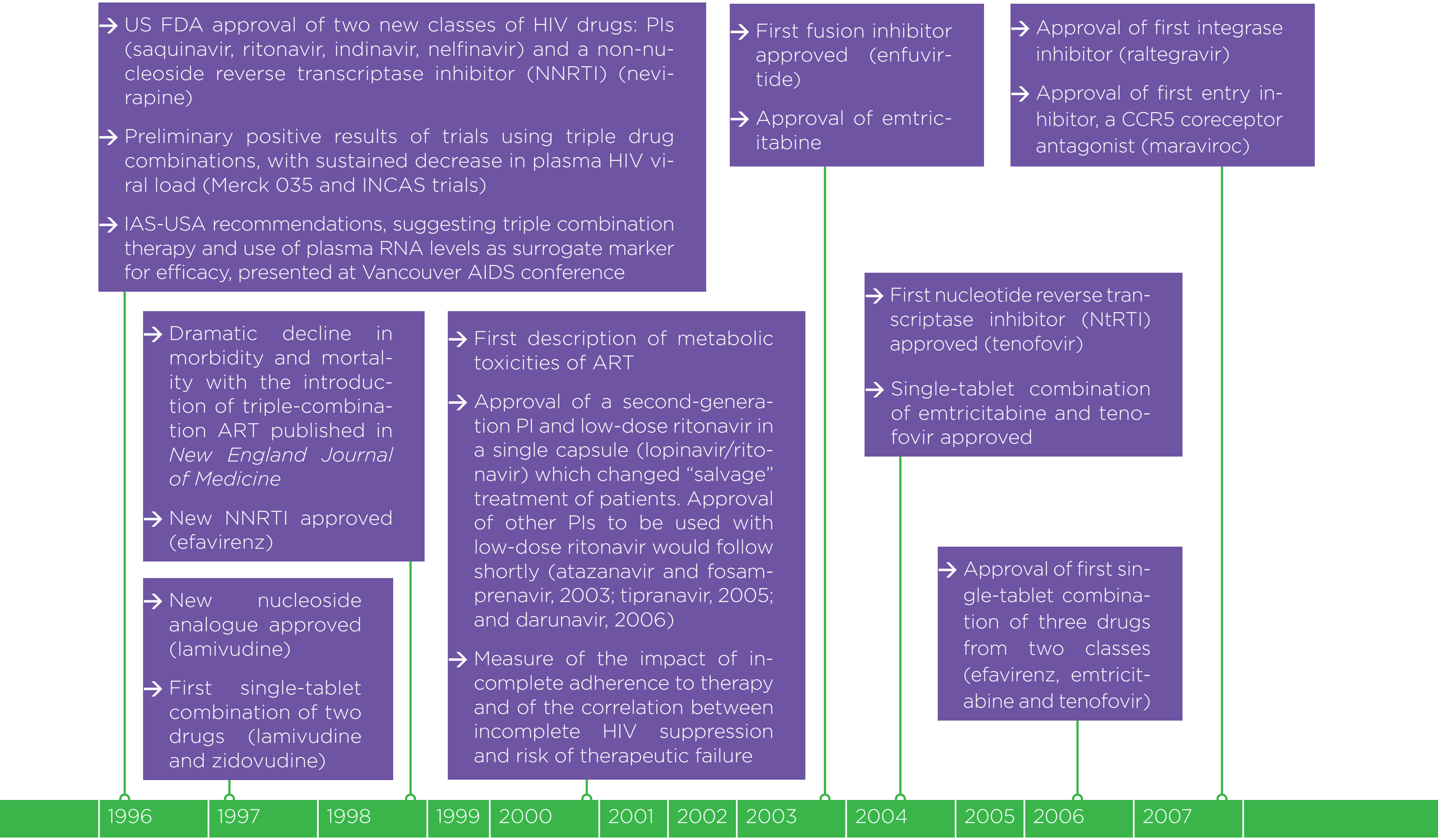
- → Concorde trial results presented at Berlin AIDS conference, demonstrating the short-lived benefits of nucleoside monotherapy and the absence of any long-term effect on survival
- → First Phase I/II trials of HIV protease inhibitors (PIs) presented in Berlin

- → Results of Phase III trials of AZT in mildly symptomatic individuals and in persons with CD4 counts less than 500

- → First description of the mechanism of HIV resistance to AZT

- → Introduction of other NRTIs: didanosine, zalcitabine and stavudine

- → Demonstration of the possibility of reducing mother-to-child transmission through antiretroviral treatment of HIV-infected mothers



- → US FDA approval of two new classes of HIV drugs: PIs (saquinavir, ritonavir, indinavir, nelfinavir) and a non-nucleoside reverse transcriptase inhibitor (NNRTI) (nevirapine)
- → Preliminary positive results of trials using triple drug combinations, with sustained decrease in plasma HIV viral load (Merck 035 and INCAS trials)
- → IAS-USA recommendations, suggesting triple combination therapy and use of plasma RNA levels as surrogate marker for efficacy, presented at Vancouver AIDS conference

- → New nucleoside analogue approved (lamivudine)
- → First single-tablet combination of two drugs (lamivudine and zidovudine)

- → Dramatic decline in morbidity and mortality with the introduction of triple-combination ART published in *New England Journal of Medicine*
- → New NNRTI approved (efavirenz)

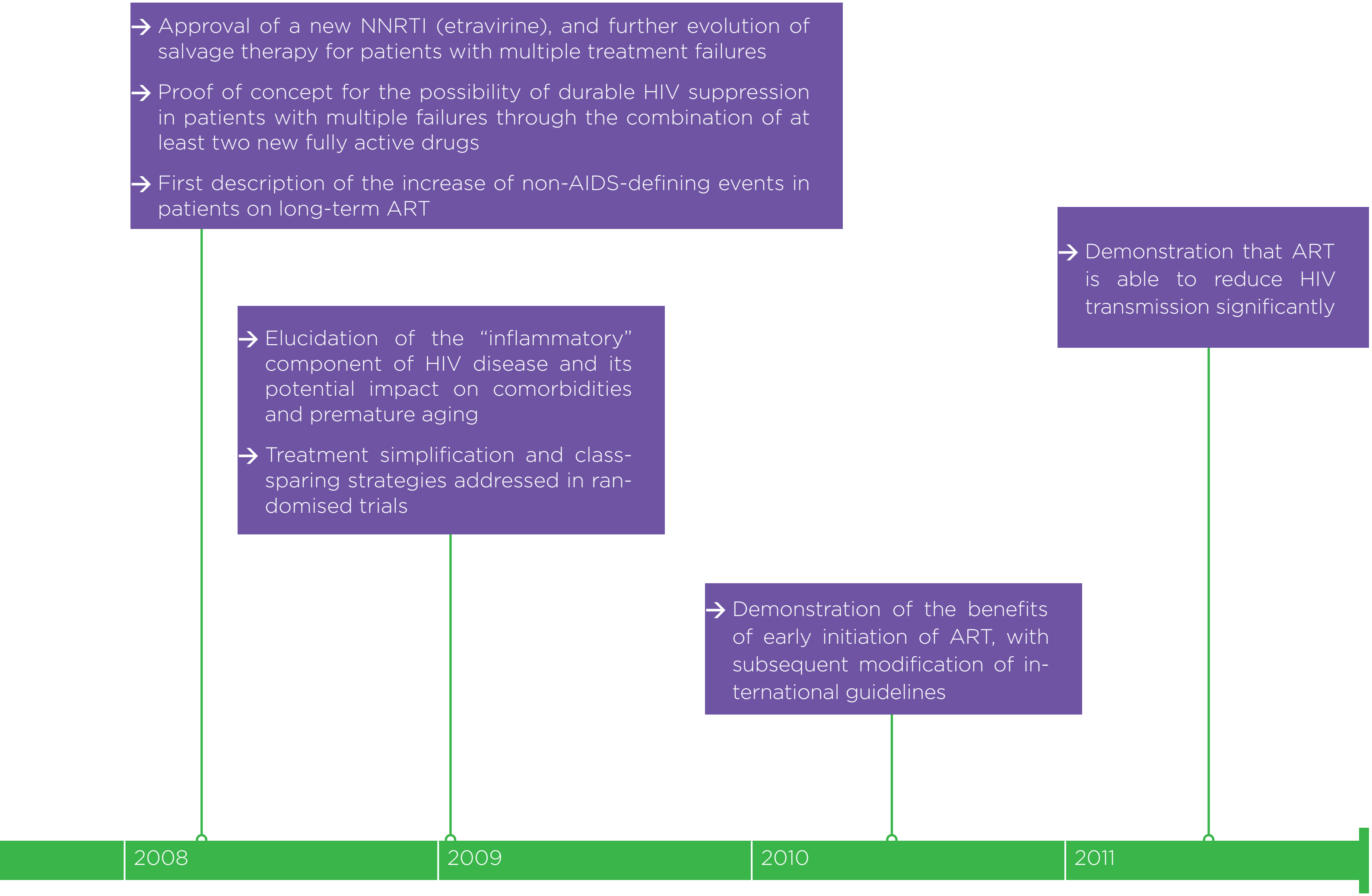
- → First description of metabolic toxicities of ART
- → Approval of a second-generation PI and low-dose ritonavir in a single capsule (lopinavir/ritonavir) which changed “salvage” treatment of patients. Approval of other PIs to be used with low-dose ritonavir would follow shortly (atazanavir and fosamprenavir, 2003; tipranavir, 2005; and darunavir, 2006)
- → Measure of the impact of incomplete adherence to therapy and of the correlation between incomplete HIV suppression and risk of therapeutic failure

- → First fusion inhibitor approved (enfuvirtide)
- → Approval of emtricitabine

- → First nucleotide reverse transcriptase inhibitor (NtRTI) approved (tenofovir)
- → Single-tablet combination of emtricitabine and tenofovir approved

- → Approval of first single-tablet combination of three drugs from two classes (efavirenz, emtricitabine and tenofovir)

- → Approval of first integrase inhibitor (raltegravir)
- → Approval of first entry inhibitor, a CCR5 coreceptor antagonist (maraviroc)



→ Approval of a new NNRTI (etravirine), and further evolution of salvage therapy for patients with multiple treatment failures

→ Proof of concept for the possibility of durable HIV suppression in patients with multiple failures through the combination of at least two new fully active drugs

→ First description of the increase of non-AIDS-defining events in patients on long-term ART

→ Elucidation of the "inflammatory" component of HIV disease and its potential impact on comorbidities and premature aging

→ Treatment simplification and class-sparing strategies addressed in randomised trials

→ Demonstration of the benefits of early initiation of ART, with subsequent modification of international guidelines

→ Demonstration that ART is able to reduce HIV transmission significantly

Source: Vella et al. The history of antiretroviral therapy and of its implementation in resource-limited areas of the world. *AIDS*, 2012, 26:1231–1241.

WHY IS IT IMPORTANT THAT THE EATG EXIST?

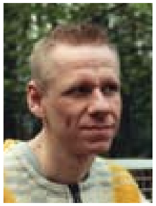
Because the EATG responds to the reality that:

- size matters in clinical research and in seeing treatment effects in our communities;
- information about clinical research results needs to be accurate and understandable;
- specific expertise is required to inform clinical research about community needs;
- access to treatment and care is unduly limited;
- knowledge about real life experience can be accumulated and refined;
- too little political attention is given to issues of HIV, infectious hepatitis and TB; and
- an organised group of individuals can express a shared position with greater force.

—Matthias Wienold, 2012

IN MEMORIAM

The EATG exists because HIV is a killer. ECAB meetings begin with a minute of silence to remember all those who have died – and who continue to die – without access to effective treatment. In the words used to dedicate the very first issue of the *EATN*, the members on the incomplete list on the next page have been “invaluable partners and friends to us and to the cause of our fight against the disease that finally caught up with them.”



Andreas
Salmen
(†1992)

Marc
Regnard
(†1992)

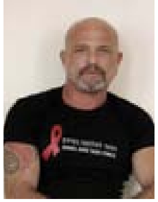
Michael
Fischer
(†1992)

François
Wasserfallen
(1962–2008)

Jan B.
Haan
(†1993)

Cord
Ebeling
(†1993)

Dick
Dirks
(†1994)

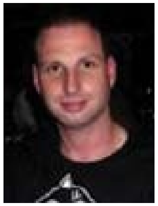


Gideon
Hirsch
(1960–2008)

Olov
Wendelborg
(1963–1994)

Nathalie
Dagron
(1960–1995)

Jeannine **van**
Woerkom
(†1997)



Roy
Arad
(1978–2010)

Marina
Bichetti
(†1997)

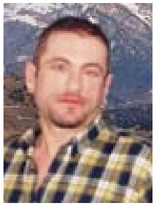
Jørgen Haahr
Kristensen
(†1997)

Jürgen
Poppinger
(†1997)

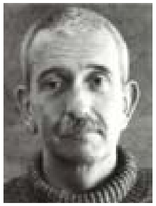
Jerzy Jurek
Domaradzki
(1949–2011)

Julio
Silveira
(†1997)

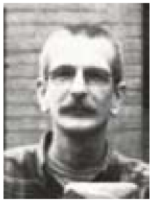
Svetlana
Denk
(†2001)



Pedro
Jorge
Eduardo **da**
Silva Santos
(1962–2002)



Arjen
Broekhuizen
(1955–2004)

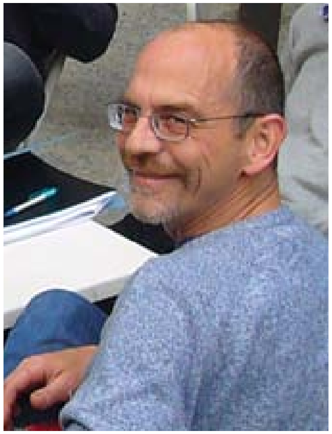


Eric J.
Welling
(1956–2004)

Albert
Rúnar
Aðalsteinsson
(1950–2006)

VOICES

Matthias WIENOLD



In 1991 there were only a few treatment activists in Germany, but we made a big splash. We marched on Christopher Street Day collecting donations for the suffering pharma companies, stormed Bristol-Myers and the national AIDS conference, held die-ins in various public places, spoke to everyone on breakfast TV, and generally made ourselves heard and seen.

Andreas Salmen and Jürgen Poppinger were the ones driving the actions on treatment and research issues. Together we began to forge links to other activists abroad. We knew we needed to collaborate beyond individual meetings and conferences; we needed a European platform to address national differences in treatment access, and to make available the research that was being kept under wraps by special interests, whether national, commercial or academic.

The EATG met for the first time in 1991 and 1992 at the Deutsche AIDS-Hilfe offices on Nestorstraße, off Kurfürstendamm. We stayed in third-class hotels and private homes. We used fax and telephone to communicate; costs were prohibitive, so the French used Minitel, the Dutch HIVnet [Internet precursors]. No email back then. In the evenings we would go out together and have a drink, often staying out late into the night discussing what we could do to improve our lots. Occasionally someone might take a break from the programme to visit a friend who was grieving or dying – or just to have a good time in a sauna.

Late one evening we went for drinks near Potsdamer Platz, which was still an empty space divided by remnants of the Berlin Wall. There was snow, and we had a snowball fight. Exhausted, we clambered onto a much smaller wall close at hand, and Robin Gorna yelled out, “This wall must come down!” That made us all laugh. We said yes, we must tear down the walls between community and industry and academic research, we must tear down the wall between AIDS in the East and AIDS in the West. Now I find myself laughing again: here we are, 20 years later, with the same challenges before us. But today at least there are ten times as many fellow activists to address them.

I was quite busy at DAH in those days. And my work didn’t always win me friends. My French counterparts called me a murderer for not promoting condoms for oral sex, while my DAH colleagues called me a pharma-whore for securing large grants from industry. The EATG gave me the opportunity to engage in meaningful discussions with clinicians and industry researchers. Most of the money I raised was spent on German projects, but I also secured some restricted funds for EATG projects and the AIDS & Medication meetings.

When I stepped down as the EATG’s executive director after three years, I joked with Robin that I would have to let our baby start taking steps on its own. I would later recall this image often. It is heartening to see that the EATG remains young and strong, sometimes even proud of its parents though still retaining its independence. I place great stock in the EATG and I hope to be around for the next big anniversaries in 5 and in 30 years.

Lisa POWER

I started working for THT (the Terrence Higgins Trust) in 1996, back when a lot of treatment work was starting up. I was in charge of developing treatment information and services and I joined the EATG straight away. There was a lot of in-fighting in those days, and THT wasn't particularly welcome as we were seen as the old guard. I remember some stand-up rows with firebrand activists shouting at me. But I had served as secretary-general of the International Lesbian and Gay Association, and EATG rows were *nothing* in comparison.

I believed the EATG needed to operate on a broad front. There was a revolution in HIV service organisations from the mid-'90s with the appearance of PIs and combination therapy and the shift towards chronic disease management. At the time, a lot of HIV organisations – like the Lighthouse in the UK – had got very good at helping people die well. But they weren't so good at helping people live, and suddenly they had all these people who weren't dying clogging up their services. Everything needed to change and treatment was the key.

People were still dying in the early ART era, and those who *were* surviving still had to put up with some terrible side-effects. One of my memories from then is joking with Arjen Broekhuizen about whether his stomach was a case of Crix belly – from taking Crixivan – or simply due to him getting older and enjoying too much good Dutch beer.

In my first years with the EATG, our meetings were all in Düsseldorf. The food was terrible and the only local attraction was a leather museum. Clearly, we went there because we were passionate about the work.

I remember at my first ECAB meeting it was Rob Camp's birthday, and so of course someone stole him a stuffed pheasant from someone's garden. During the course of the meeting, I remember that the damn bird kept on turning up in different people's rooms.

In the beginning, the pharma reps tended to be PR flacks – sometimes even young dolly-birds who were used to chatting up doctors – and some of our people knew much more about the science than they did. And most of us were gay anyway. The companies have learned, of course. Nowadays they send bright gay men or Africans....

In the late '90s, there were perhaps a dozen core members. We had some problems with the secretariat – poor management. Because so many people who were activists for the EATG in the early days were seriously ill, we sometimes had them shadow each other – meaning that we had two people be responsible for the same job, since you never knew if one of them might suddenly keel over.

Today, the EATG has become much more integrated with national and international NGOs. And the staff is certainly much more professional. But I think it's important for us to remember all the things we can thank the founders and the early members for – for instance, the work they did to get pharmas to start thinking about the actual experience of taking their drugs.

Jens WILHELMSBORG

I had a career with the Danish Foreign Service. I was stationed in San Francisco and tested positive for HIV in 1993.

I first became involved in the EATG as a guest of ECAB in 1997, becoming a member in 1999. I joined the board of directors in 2001, serving as treasurer, from 2001 to 2005. In 2004 I was also responsible for office oversight and the move from Düsseldorf to Brussels. Today I'm chair of DMAG.

The EU has provided some funding for the EATG since 1997, starting with the treatment newsletter *EATN*. Although pharma has been our largest funder, their grants were unrestricted and unconditional; their support has *never* posed a problem. At the same time, the EATG's professionalism has ensured that we've kept the respect of the advocacy community.

My biggest thrill was the first EU hearing that we arranged, on AIDS and public health, in May 2000. Fortunately, we were able to obtain the sponsorship of Finnish MEP Heidi Hautala, and the meeting opened a lot of doors for us. I was in the Lobbying Working Group, and we felt very successful when we were able to suggest amendments for the EU's Public Health Programme proposal – and when the Parliament eventually adopted one of them.

Expanding our efforts to southern Europe was a big step. The governments in northern Europe were more responsive to the concerns of treatment advocates, who were themselves more experienced politically.

Our biggest challenge today is the EATG's expansion in the eastern European region. In terms of epidemiology and access to HIV medicine, things are pretty much under control in the West – though with the financial crisis, we may well see the situation regress, especially for migrants.

INITIATIVES

THE CRIMINALISATION OF HIV transmission and exposure

International Guidelines
on HIV/AIDS and Human Rights
2006 Consolidated Version

Second International Consultation on
HIV/AIDS and Human Rights
Geneva, 23-25 September 1996

Third International Consultation on
HIV/AIDS and Human Rights
Geneva, 25-26 July 2002

Organized jointly by the Office of the United Nations
High Commissioner for Human Rights and the
Joint United Nations Programme on HIV/AIDS

For the EATG, the criminalisation of HIV transmission or exposure is a hot issue that can really get members' blood boiling. Why is HIV transmission, of all infections, singled out? Don't the experts and authorities realise that by criminalising it, they actually increase stigma and discrimination, which can then lead to further transmission? This cockamamie approach, even part of the law in some European countries, has to come to an end.

The EATG took its first major step to address the issue in October 2006, when as a part of its memorandum of understanding with WHO Europe, a technical consultation on criminalising the transmission of and exposure to HIV and STIs was held in the WHO office in Copenhagen. The consultation brought together representatives and technical experts from PLHIV organisations, NGOs, health ministries, WHO and UNAIDS. After hearing about various experiences in European countries, the consultation identified an urgent need for further collaborative action, including a position statement from WHO or the UN.

During the meeting it became clear that criminal law and public health programming are two distinct systems addressing different social structures and needs. Participants expressed concern that HIV was being singled out for prosecutions in most jurisdictions that allow for it, and that the focus was almost exclusively on sexual transmission or exposure, an issue the EATG had highlighted earlier.

Participants recommended that the criminalisation of HIV/STI transmission should be a last resort and only undertaken in a manner consistent with international human rights obligations, as outlined for example in the *International Guidelines on HIV/AIDS and Human Rights*. The resort to criminalisation can be seen as a failure of prevention efforts, further highlighting the need for greater efforts on that front, including measures to overcome stigma and discrimination that undermine prevention.

The EATG was well represented at the consultation. And as the issue is far from resolved, it will be convening a major European meeting on the matter in late 2012 and developing a position paper.

KEY ISSUES

❶ How is "harm" understood in the context of criminal liability?
❷ Should states enact HIV/STI-specific offences – or, in appropriate cases, should they apply existing general offences?
❸ Should criminal law be limited to HIV/STI transmission or be extended to exposure?
❹ How *should* we address intentional transmission or exposure?
❺ Should consent preclude criminal liability, and what constitutes consent?
❻ What is the impact of criminalisation on public health?
❼ How do we establish the causal link (proving infection by the defendant)?
❽ What is proper conduct of police investigations and prosecutions?
❾ How do we ensure privacy rights: confidentiality of communications with service providers?


Halve It
Halve It
Use condom
get tested
Halve
HIV in Europe 2007
We are not getting PLWHA to care early enough
HIV in Europe 2007

HIV IN EUROPE Initiative

In 2007, the HIV in Europe Initiative was founded by the EATG, AIDS Action Europe, the Copenhagen HIV Programme and WHO at a major conference in Brussels attended by the European Commissioner for Health. Dedicated to improving early HIV diagnosis and care throughout the European Region, the initiative provides a European platform for the exchange of research findings and the promotion of related activities. The initiative is directed by an independent group of experts who represent civil society, policy-makers, health professionals and European public health institutions.

HIV in Europe is not an organisation, but an initiative formed to inform processes, share knowledge and improve the evidence base around key issues of earlier testing and care. The initiative has launched and funded several major efforts to enhance optimal testing and care, addressing the criminalisation of HIV, indicator diseases that should trigger an HIV test, documentation of stigma and discrimination and community testing initiatives (see box).

The initiative has been successful in putting the issue of earlier diagnosis high on the political agenda in Europe. Its crosscutting efforts to date were on full display at its 2012 conference in Copenhagen, where the more than 300 participants from 46 countries included 37% community representatives, 25% clinicians and 15% policy-makers. The conference culminated in a new call for action to focus on HIV testing in Europe in the coming years.

> "The introduction of effective antiretroviral treatment (ART) in the mid 1990s heralded a new era in the management of HIV/AIDS, offering the potential for improved health for individuals coupled with profound public health gain for society. The incentives for HIV-seropositive individuals to know their status appeared to be substantial. However, the advances in treatment have not resulted in the overall health benefits that were expected."
>
> *—Testing Times: Unmet Need in Testing, Treatment and Care for HIV/AIDS in Europe*

→ **www.hiveurope.eu/LinkClick.aspx?fileticket=iRD2x3L0GLE=&tabid=96**

❶ CONSENSUS DEFINITION OF LATE PRESENTATION FOR HIV

A common definition of the term “late presenter” is essential if late presentation is to be more effectively dealt with by public health authorities across Europe and elsewhere. Two initiatives, HIV in Europe and “Late presentation for HIV treatment in Europe”, joined efforts in Spring 2009 to identify a common definition of a patient presenting late for care. To see the definition or view the publication in *HIV Medicine*, please visit www.hiveurope.eu.

❷ ESTIMATION OF THE UNDIAGNOSED POPULATION

Surveillance to identify the exact extent of the undiagnosed population remains insufficient across Europe. Different estimation approaches exist, using different sources of data, and many countries do not appear to produce any estimates. This project group has worked to create a guidance document for countries on data requirements and available methods for estimation of the number of people with HIV. The document outlines all available approaches and provides the necessary guidance for using them. It is the first step towards a coordinated European approach.

❸ HIV INDICATOR DISEASES ACROSS EUROPE

The concept of indicator disease-guided testing is an approach by which health care practitioners can be encouraged to test more patients based on suspicion of HIV. Little evidence on HIV prevalence exists for various conditions and diseases where HIV prevalence is thought to be higher than in the general population. The HIV in Europe pilot study assesses HIV prevalence in 8 indicator diseases in specific populations. The study includes 17 centres in 14 countries and is enrolling 7000 people presenting with an indicator disease.

❹ THE PEOPLE LIVING WITH HIV STIGMA INDEX

In 2008, GNP+, the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF) and UNAIDS presented the People Living with HIV Stigma Index. The Index aims to build the evidence base for understanding stigma and discrimination experienced by people living with HIV in different countries. HIV in Europe is supporting the implementation and roll-out of the stigma index in Poland, Ukraine, Estonia, Moldova and Turkey.

❺ CRIMINALISATION OF HIV ACROSS THE EUROPEAN REGION

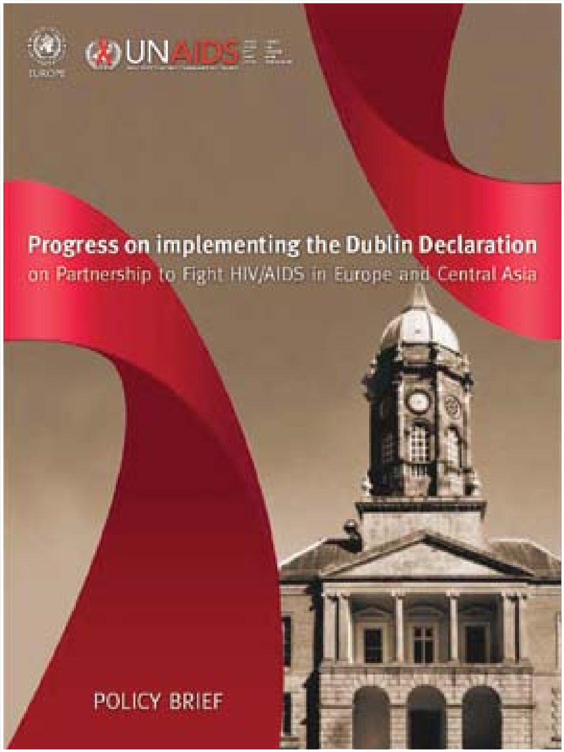
The aim of this project is to review legislation across the European Region that singles out the criminalisation of HIV or any other communicable disease, and describe such laws, the reasoning for them, and whether they have had any effect on the spread of the disease in the country including their potential impact on testing.

To identify political, structural, clinical and social barriers to achieving optimal testing and care

You are here:- Call to Action .. Call to action 2012-2014

> “HIV in Europe is not an organisation, but an initiative formed to inform processes, share knowledge and improve the evidence base around important issues of earlier testing and care. It is unique in its collaboration between stakeholders from clinical, advocacy and public health backgrounds.”
>
> *—www.hiveurope.eu*

CIVIL SOCIETY FORUM



Progress on implementing the Dublin Declaration
on Partnership to Fight HIV/AIDS in Europe and Central Asia

POLICY BRIEF

Policy brief for Dublin Declaration progress report

January 2005 saw a major breakthrough for civil society organisations in the European Union. The EATG and other civil society organisations were finally afforded the opportunity, through a formal mechanism, to engage with the top policy-makers in Europe. The European Commission's HIV/AIDS Think Tank established a subgroup for informal consultation with civil society, known as the Civil Society Forum for HIV/AIDS. Today it involves some 30 NGOs and other civil society organisations from across the WHO European Region. The role of the Forum has been to advise the Commission on the implementation of HIV policy and identify related issues that need to be addressed. In its role, the Forum comments on HIV policy proposals and activities, as well as priorities in the Public Health Action Programme's annual work plan.

Participating organisations are selected by the HIV/AIDS Task Force of DG Sanco on behalf of the Think Tank for renewable two-year terms. Initially an observer on the Civil Society Forum, the EATG later became a co-chair together with AIDS Action Europe.

One of the Civil Society Forum's first major contributions was providing valuable input on the *Communication from the Commission to the Council and the European Parliament on Combating HIV/AIDS within the European Union and in the Neighbouring Countries, 2006–2009*. Building on European commitments made in the UNGASS, Dublin and Vilnius declarations, the Communication stated that one of its chief aims was "to strengthen the involvement of civil society in all aspects of the response to the epidemic, including policy development, implementation, monitoring, and evaluation". In addition, it supported the development of indicators to monitor the Dublin Declaration (see below), a process in which the EATG played a pivotal role, first in conjunction with WHO Europe and later with the ECDC.

AN ORGANISATION APPLYING TO THE CIVIL SOCIETY FORUM HAS TO FULFIL THE FOLLOWING CRITERIA:

➊ The organisation has to fit within the following definition: "Civil society organisations are all non-profit, organised groups, clubs and associations in society that operate independently from government and the state[,] except firms and political parties".

➋ The organisation has to have its main base of operation in a[n EU] Member State, candidate country, EEA country, Russia or European Neighbourhood Policy country.

➌ HIV activities must constitute a major focus of the organisation's work.

➍ The organisation has to be either: 1) a patient organisation, 2) an NGO working in or with affected communities or 3) a European network or umbrella organisation in the HIV field. Qualifying organisations include those focusing on specific themes related to HIV (e.g. injecting drug users, men who have sex with men, migrants, sex workers, etc.).

➎ The organisation has to have sufficient presence in the local area, preferably on a national level.

➏ The organisation should be in regular communication with other local NGOs to enable it to represent its national HIV situation well and serve as a national focal point.

In its 2010 advocacy training manual, *HIV/AIDS Treatment Advocacy*, the EATG identified the Dublin Declaration as a touchstone for HIV advocacy in the European Region. In the report *Progress on Implementing the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia*, several broad imperatives emerged for European HIV efforts. They include:

- establishing greater accountability;
- amending legal and regulatory frameworks to enable them to better address HIV-related stigma, exclusion and discrimination;
- strengthening national and regional HIV and STI surveillance;
- improving and harmonising monitoring and evaluation efforts, including greater disaggregation of data for key indicators;
- intensifying, scaling up and improving the targeting of HIV efforts to reduce inequities;
- working for greater harmonisation of the highest standards of prevention and treatment programmes and policies;
- expanding the use of internationally recognised evidence-based interventions;
- strengthening cooperation between countries on such efforts; and
- increasing civil society and private sector involvement.

The policy brief issued in conjunction with the progress report includes lists of recommendations, organised thematically, that provide an invaluable blueprint for action on HIV in the European Region.

"For me, the 2007 ARV4IDUs seminar in Vilnius was my most memorable experience. I felt part of something vital, as if the seminar might make a difference. Professionally, it was also a huge challenge for me to run the seminar by myself. My flight was delayed for a day and some speakers couldn't get into the country. The office in Belgium wasn't open as it was the weekend, so they could do little for me from there. People were complaining about the food and the roughness of the towels. I had to deal with big and small stuff all the time and was supposed to simultaneously moderate discussions. And meanwhile I had a painful limp after an operation had failed to fix my foot. It was daunting."

—Lies Verhetsel, former training
and project coordinator

THE EATG AND WHO EUROPE

from Berlin to Berlin

The year 2005 was a turning point in the EATG's collaboration with WHO. WHO Regional Office for Europe worked closely with the EATG in planning its first technical consultation with civil society, which took place in Berlin in October. In fact, the focus of the conference *was* collaboration between civil society and international health agencies such as WHO and the ECDC.

This was the first broad consultation WHO Europe had had with people in the trenches and as seen in the years following, it helped it become more of an advocate for community-led initiatives. In the months that followed the consultation, WHO Europe signed its first memoranda of understanding with HIV civil society groups: the EATG Action Europe, as the major pan-European HIV and AIDS organisations. The MoU with the EATG states:

Where possible and appropriate, the Parties wish to collaborate in the following areas:

- the development of normative work such as relevant treatment and care protocols;
- advocacy to create and sustain momentum for prevention, treatment and care;
- priority research topics;
- treatment preparedness;
- the sharing of resources, even prior to publication when possible; and
- relevant long-term planning for the scaling up of HIV/AIDS prevention, treatment and care in WHO European Region.

For the EATG, the Berlin consultation resembled the sort of meetings that the EATG aspired to, while providing a great opportunity for the organisation to better understand the work that WHO was doing. In the opening session, Nikos Dedes (EATG) described WHO as a good, respectable partner in the fight against HIV in the European Region, but one that had in the past been rather distant towards community-based organisations. He said that while the urgency of the unfolding epidemic might make such distance understandable, it was critically important to improve the working partnership, especially since the Region was home to some of the world's fastest-growing national epidemics. Other memorable moments included Mick Mathews from the Global Fund discussing its engagement with the community, noting "that without civil society, there would be no government response to the epidemic"; Lital Hollander (EATG) on sperm washing; Bernard Gardiner (International Federation of Red Cross and Red Crescent Societies) presenting the Code of Good Practice for NGOs Responding to HIV/AIDS; and Mauro Guarinieri (EATG) explaining how anger and a sense of injustice are appropriate, necessary responses to the epidemic.

Since Berlin, the EATG has continued to expand its engagement with other international entities such as the ECDC, the EMCDDA, the European Commission and the EMA. And in late 2012, the EATG will return to Berlin to address the criminalisation of HIV transmission and exposure – and WHO Europe will be right there with it.

From the Berlin 2005 WHO Europe technical consultation with civil society

Report of the WHO European Region Planning and Technical Consultation on working with civil society to scale up access to HIV prevention, treatment and care

Berlin, 5-7 October 2005

THE EUROPEAN COMMUNITY ADVISORY BOARD (ECAB)

ECAB IS CHARGED WITH:

- reviewing the design of clinical trials;
- reviewing informed consent forms for content and language;
- monitoring adverse events, compliance and community needs;
- obtaining interim results;
- cultivating relationships with investigators and other researchers; and
- maintaining visibility to all parties involved in clinical trials, particular the community of patients who are participating.

The EATG has played a central role in scientific development since its early days. Nothing exemplifies that better than ECAB. The EATG founded ECAB in autumn 1997 to facilitate more productive interaction among pharmaceutical companies, researchers and European PLHIV in research and development on new treatment agents.

ECAB, which now boasts 70 members from some 30 countries, invites companies and researchers to meet with it – on *its* terms. The advisory board picks the hotel and meeting room and pharma representatives attend as guests. Advocacy and empowerment are key values for ECAB, and it also arranges internal meetings to share information with members and conducts trainings to increase their expertise on topics such as research methodology, statistics, immunology, resistance, regulatory processes and diagnostics.

Since its founding, ECAB has battled all forms of discrimination based on prejudice or politics. It consistently advocates for greater participation and inclusion of women, people who use drugs, people of colour and other populations in clinical trials and drug development, in order to better reflect reality and the real-world face of HIV in Europe. In recent years, ECAB has also helped form community advisory boards in eastern Europe and made TB and hepatitis coinfections a fast part of its agenda.

THE TRAINERS' POOL

Since the early years of its existence, the EATG has offered trainings in treatment literacy and treatment advocacy. These trainings have helped the organisation to develop regional and international networks of treatment activists, and to train activists who would later become EATG members.

While the organisation's membership and activities were initially concentrated in western Europe, the training initiatives helped it expand to southern, central and eastern Europe fairly rapidly. They complemented the EATG's other capacity-building efforts, notably the translation of treatment leaflets and brochures as part of the Continuous Patient Education Project (COPE) for use in central and eastern Europe. However, after sponsoring training workshops at conferences in these regions for many years, the EATG suspended its training efforts due to a lack of funding and capacity.

In 2009–2010, an operational grant from the European Commission enabled the EATG to create a trainers' pool. This grant has allowed the organisation to renew its emphasis on training and other capacity-building activities. Since then, it has produced manuals devoted to treatment literacy and treatment advocacy.

In 2012, an EATG meeting in St. Petersburg combined a training workshop with the development of a common workplan for local Russian NGOs and a policy dialogue meeting with international institutions including UNAIDS and WHO.

MORE VOICES

Ferenc BAGYINSZKY

I've been with the EATG for some five years. One of the things that's always impressed me has been the mixture of people involved and the fresh perceptions they bring – things I never would think of. I remember once we were in a meeing with a bunch of legal experts, discussing a brief on the criminalisation of HIV transmission, when a new EATG member asked, *Have you considered whether this could be applied to mother-to-child transmission?*

I joined the EATG because there is hardly any patient community in Hungary, being a low-prevalence country, and due to our history civil society is quite weak. The EATG has enabled me to bring national HIV issues before the EU – and bring EU information and positions back to Hungary, where I work at the Hungarian Civil Liberties Union.

One of our most important challenges is getting members to be active – *transformative* – conveyors of information. What do they do with the information they acquire from the EATG when they return to their countries, their communities? And are we informed about what's going on at the national level?

The EATG has a fairly flat organisational structure, a diverse membership, many partners and many projects. That means that perhaps the biggest challenge we face is prioritising – deciding where to invest our energy – which partly falls on my shoulders as the chair of the board of directors.

Koen BLOCK

I first heard about the EATG in 1996, when I was working for Sensoa on getting the first protease inhibitors introduced to Belgium. I became a member in 1998 and I joined ECAB as twin to a Belgian colleague. I joined DMWG in 2000 after the Athens GA when the group was still preparing the handbook (which was approved at the next GA in Brussels).

There were lots of working groups back then: the XX Study Group for women, the Eastern States Working Group, the Lobbying Working Group and so forth. For every new need that arose, it seemed like a new working group did too. Finally we realised that many of the groups could – and should – be integrated. Today we're organised around three pillars: research, policy and training.

From the very start, the EATG met directly with pharmaceutical companies – a new approach for a patient organisation. The EATG showed how important it was to collaborate and how to still be very critical when needed. However, we're still criticised in the patient community for our relationship with Big Pharma.

Before I served on the Board of Directors for one term, I was involved in the Lobbying Working Group (later the Policy Working Group) and the Trainers' Working Group. In 2009, I became the first member joining the office as a paid staff member [*executive director!*].

Today we have over 110 members from 30 countries. The broad differences that the members represent will always be a source of challenges. Differences in national culture, in community dynamics, in epidemiology, in political conditions. But those differences are also the source of our strength.

Luis MENDÃO

In September 1996, after a very difficult year in which my finances, work situation and health had deteriorated rapidly, I was taken to the hospital emergency department of Santa Maria, Portugal, having found myself in an almost grotesque situation: I could not get off the couch to visit, as I'd promised, the Lisbon nightlife with a Dutch friend. I was hospitalised for a week and was examined, X-rayed and ultrasounded, and I slept like never before.

The doctors did not tell me anything about my condition, and my personal physician, a director, never even showed up. On the seventh day, a young doctor on duty closed the door and told me that my situation was very grave. "Do you have any suspicion of what it might be?" he asked. "No," I replied. The young doctor looked desperate, and finally said, "It might be HIV."

I have AIDS, that's it, it makes sense, everything makes sense – mortal fatigue, lung and eye problems, viruses, infections, even the lost pounds!

Three years later, I joined the EATG at the suggestion of the outstanding Pedro Silvério Marques, friend and co-conspirator for more than a decade. Then in 2001 we founded GAT at an EATG meeting in Athens. Over the years I served on the EATG board and relentlessly attended meetings and conferences all over the world, as well as at home when Pedro and I worked closely with the esteemed Portuguese AIDS Commissioner Henrique Barros to organise a European ministerial conference on HIV and migration during the Portuguese EU Presidency.

Postscript 2002: After a liver biopsy which showed grade 4 fibrosis, I took pegylated interferon and ribavirin for 12 weeks with no results whatsoever except for serious side-effects. At present I have no credible treatment options for hepatitis C and my death risk from liver disease progression is much higher than from AIDS. I'm cirrhotic now. I smoke (a lot) but I do not drink alcohol.

Postscript 2012: CD4 count is even higher, viral load undetectable, age and hepatitis C caused some damage, but 95 kg, still loving people, life, thinking, learning and doing. Still a little insane, part of insane organisations with insane aims....

Shona SCHONNING

My first exposure to the EATG was in 1995. I was working at an HIV information service for Russian NGOs and saw the *EATN*, one of the very few publications we had that provided news on treatment. Back then, very few PLHIV in Russia knew their HIV status – and even fewer needed treatment.

I had no way of knowing then that, 10 years later, highly effective treatments would exist – or that there would be so many people in eastern Europe and central Asia who needed such treatment but would have no access to it. Nor did I know then that 10 years later I would be recruited to become an EATG member and help fight for better access to treatment.

One of the first EATG events that I participated in as a member was five years ago, the Lisbon conference on HIV and migrants. From the start, I was impressed at how this group of experienced activists, most of whom had good access to treatment in their own communities, were working to improve the situation for people in other communities that were struggling to survive. In particular, I was impressed with their deep sincerity, scientific rigor and reliance on their "sense of justice," as Luis Mendão put it in his closing speech. I felt proud to be a part of the organisation.

Since then, the EATG has mentored me, provided me with a chance to be heard (by its members, its partners and its stakeholders), and given me abundant opportunity to collaborate with dedicated and experienced activists and experts to promote access for those who still lack it.

Raminta STUIKYTE

My background is in drug policy and harm reduction. And in eastern Europe, that means dealing with HIV, as well as hepatitis C – and a lot opposition from certain governments. I've been a member of the EATG for some time, but when I left as head of what is now known as the Eurasian Harm Reduction Network, I wanted to find a way to stay involved in the region. So it was natural for me, having already been an EATG member for some time, to assume a more active role in the Policy Working Group.

Looking back, I think the migration and HIV conference in June 2007 was one of my favourites: a unique platform bringing together people from migration groups, research institutions, Roma/Sinthi, technical agencies, HIV community groups, and groups working on HIV among disproportionally affected minorities, like Russians in the Baltic states or central Asians in Russia. We developed HIV and migration recommendations from a community perspective and translated them into multiple languages (Russian, Portuguese, Italian, English and probably others once the ball started rolling). We presented them at a high-level event on HIV and migration later that year sponsored by the Portuguese presidency of the EU. Some countries reviewed their practices, and national governments were also mobilised to request that the UN address migrant issues in its HIV programmes. Now they are also regularly addressed as part of Dublin Declaration monitoring.

One of my priorities now is working to ensure that new EU member states deliver on their promise to deliver universal access to HIV services, despite having pretty much the same pharmaceutical prices but a per-capita pharmaceutical expenditure that's only a third of what it is for older member states. In the context of the European economic crisis, it's a daunting task, and my great fear is that countries will focus on their financial sectors and not the health of their own populations. And that's particularly true for people living with HIV, people who inject drugs and other risk populations.

Another challenge has been to bring drug policy issues into the HIV field and HIV policy issues into the drug field. The EATG facilitated the development of recommendations for the EU drug policy in two civil society forums – one on HIV and the other on drugs. We helped develop common positions for groups like the Eurasian Harm Reduction Network and AIDS Action Europe within the Civil Society Forum on HIV/AIDS, and for groups like the International Drug Policy Consortium, San Patriagno and the Scottish Drugs Forum within the Civil Society Forum on Drugs. Right now we are following up to push for the incorporation of human rights in the EU drug strategy. It's a new but essential issue for the EATG.

Wim VANDEVELDE

Less than a year after my HIV diagnosis in 2000, my doctor introduced me to the fabulous four Portuguese members of the EATG in what would become a life-altering series of events. Soon after the initial contacts, I was invited to participate in the southern European treatment activist training organised by the EATG, and a whole new universe opened up for me.

Prior to my introduction to the EATG, I had little to no knowledge of HIV. A few friends of mine had died of AIDS, but my personal involvement in the cause had been almost non-existent until the virus found me. Slowly but surely, my priorities in life began to change, and as I became totally consumed by the activist virus, I eventually abandoned my previous career.

I felt immediately attracted to this strange group of passionate activists from all over Europe, and I remember well my first ECAB meeting in Brussels as a guest. At first I was desperate because I understood next to nothing of what was being said at the meeting, yet the people were extremely welcoming and made me feel that I belonged. Though today I still grasp only a fraction of the vast science of HIV, I have nonetheless tried to contribute to the development of this organisation, which I have come to consider a second family.

In my elected positions and serving with my dear colleagues on the board, I have always worked to safeguard the uniqueness of the group by increasing the professional support staff and by harnessing the priceless commitment of our fellow members. We have tried to improve the delicate membership balance between east and west, north and south, gay and non-gay, experienced and new, pharma-friendly and pharma-paranoid.

As one of the American ACT UP founders recently said, it is easy to demonise Big Pharma and reject its tactics, but it requires sophistication and complexity to actually talk and work with it for the ultimate sake of people living with HIV. I believe that we have succeeded in doing this within the EATG and ECAB, engaging industry as well as other stakeholders.

I cannot single out one specific moment of this past decade with the EATG as the most memorable one. It would be reductive and leave out so many extraordinary people and stories. I have laughed, shouted and cried as part of the EATG. And I have loved. I feel extremely privileged to be a small part of its history, and I know that the EATG will continue to lead in working to remove the many remaining obstacles to universal access in Europe.

Peter WIESSNER

I've been working in Germany for AIDS-Hilfe organisations for 20 years. About 10 years ago, I became very interested in getting more involved with HIV issues on the international scene, and then I met an EATG member who introduced me to the organisation. AIDS-Hilfe was able to provide me with some salary, while the EATG helped me cultivate my passion and give me access to international conferences.

I've seen a lot of change in the past decade. PWG meetings 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.

The high point of my membership so far was when the EATG let me co-organise a two-day conference on migrants' access to treatment. It was very successful, and I found it remarkable that the organisation was so willing to finance and otherwise support it.

I believe the biggest challenge ahead for us will be in staying honest, fresh and alert to Europe's changing new realities.

Anna ŻAKOWICZ

The EATG has managed to develop a model of an organisation that covers three very different areas of expertise: advocacy, research and education. We have also been able to effect political change at every level from local grassroots to European and global entities.

One critical development has been the inclusion of HCV and TB co-infections in what we do. Our work on HCV and the Sitges meetings has been invaluable in advocating for more HCV research among HIV-positive patients.

It did not happen overnight, but the EATG has become more open to membership and issues from countries that were previously unrepresented. We became more accessible to the “average” HIV activist and to people from low-prevalence countries and eastern Europe. Thanks in part to this openness, the ECAB model has begun to be emulated outside western Europe, with several new community advisory boards being formed in the past few years. In particular, ECAB has supported the EECA CAB and new national CABs in the EECA region.

In addition to the EATG efforts in central and eastern Europe, another initiative that has helped the organisation become closer to the people and issues on the ground has been the creation of a trainers’ pool.

The first time I was involved with the EATG was the ARV4IDUs meeting in Vilnius, 2007. Then I went to the Prague meeting organised by the EATG and started attending ECABs, the first at the end of 2007. I became a member in 2008, I think in the spring.

For me personally, the EATG has provided opportunities to learn about advocacy at different levels and meet courageous, like-minded people. The other members have given me strength and taught me through fun times as well as tough times. Perhaps most of all, the EATG helped me be more critical about how I as an individual am working with the PLHIV community and the stakeholders engaged in the HIV response. The journey has never been easy, but it has been extremely productive and fulfilling.

ANONYMOUS

I was diagnosed with HIV in 2006. My native country didn't have a PLHIV network at that time, and I felt very isolated. But my physician was an EATG member, and within a year I had joined. It now feels like a family to me, a community where I belong.

Initially, I sat in on a ECAB meeting as a guest, but that proved too scientific for me, especially with the rapid pace of change in the field. So I switched to the Policy Working Group, where I've been ever since, mainly involved in human rights issues such as the criminalisation of HIV transmission/exposure, labour restrictions etc. People may not realise it, but policy doesn't change – at least not very quickly!

One of the great things about the EATG is that it's a patient-led organisation, with about 60% of the members being HIV-positive. I personally believe the patient role should be emphasised even more in the organisation. I would also like to see the EATG focus more on new public health approaches.

In the last couple years, I've seen a surge in members from other under-represented countries, as well as an increase in our activities there. We helped set up NeLP [the Network of Low HIV Prevalence Countries in Central and South Europe] last year and draw up the Budapest Declaration. Earlier this year we organised a follow-up meeting in Belgrade just before the EACS conference, and we're holding another strategic and action planning workshop later this year, again in Belgrade. We need to make funders and partners aware that low-prevalence countries face rather specific challenges, because while their infected populations are small, their HIV epidemiological patterns differ significantly from those of Eastern European countries.

"I joined the EATG in August 2011 as the first member from Slovenia. I was truly honoured to be accepted, to represent and to advocate for people living with HIV in general and especially those from Slovenia. The EATG is doing a wonderful job and plays an important role in advocating for better HIV treatment in Europe. I see it as one of the strongest community groups in the HIV field, and I have already learned a lot since I joined. I want to contribute in the best way I can, advocate, spread the knowledge of treatment possibilities and build networks. I want to make people aware of the EATG and the importance of HIV treatment in Slovenia and abroad."

—Miran Šolinc

BOARD OF DIRECTORS, 1992–2012

23 February 1992 **(inaugural meeting)** – 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 Dressler[3], 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 Dagron, France; Stéphane Korsia, France

22 July 1995 **(GA election, Lisbon)** – 8 September 1996
Hans-Josef Linkens, Germany, chair; Arnulfo Gonzalez Sanchez, Spain, Stéphane Korsia, France

8 September 1996 **(GA election, Helsinki)** – 9 March 1997
Arjen Broekhuizen, Netherlands, chair; Stefan Mauss, Germany; Raffi Bhabakanian, UK; François Houyez, France; Rob Camp, Spain

9 March 1997 **(EGA, London)** – 31 August 1997
Arjen Broekhuizen, Netherlands, chair; Stefan Mauss, Germany; Raffi Bhabakanian, UK; François Houyez, France; Rob Camp, Spain

31 August 1997 **(GA election, Rotterdam)** – 25 May 1998
Arjen Broekhuizen, Netherlands, chair; Rob Camp, Spain; François Houyez, France, secretary; Raffi Babakhanian, UK, treasurer; Nico Hollander, Netherlands; 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; Filippo von Schloesser, Italy; Tytti Anneli Poutanen, Finland

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

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[3] Co-opted in after death of Marc Regnard.

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; François Houyez, France[4]; Jorma Koskinen, Finland, treasurer; Katy De Clercq, Belgium; Nikos Dedes, Greece

6 May 2001
(GA election, Brussels)
26 May 2002
Filippo von Schloesser, Italy, chair; Katy De Clercq, Belgium; Alain Volny-Anne, France, secretary; Jens Wilhelmsborg, Denmark, treasurer; Mauro Guarinieri, Italy; Robert Vercauteren[5], 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; Jens Wilhelmsborg, Denmark, treasurer; Kevin Moody, Netherlands, secretary; 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; Maxime Journiac, France

21 May 2005
(GA election, Madrid)
– 13 May 2006
Nikos Dedes, Greece, chair; Wim Vandevelde, Portugal, treasurer; Smiljka de Lussigny (née Malesevic), Serbia, secretary; Alain Volny-Anne, secretary, France

13 May 2006
(GA election, Prague)
– 24 September 2006
Nikos Dedes, Greece, chair, Smiljka Malesevic, Serbia, secretary, Wim Vandevelde, Portugal, treasurer: Koen Block, Belgium; Luis Mendão, Portugal

24 September 2006
(EGA election, Madrid)
– 6 May 2007
Nikos Dedes, Greece, chair; Smiljka Malesevic, Serbia, secretary; Wim Vandevelde, Portugal, treasurer; Koen Block, Belgium; Luis Mendão, Portugal

6 May 2007
(GA election, Stockholm)
– 25 May 2008
Wim Vandevelde, Portugal, chair; Koen Block, Belgium, treasurer; Smiljka de Lussigny, Serbia; Alain Volny-Anne, France, secretary

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[4] Stepped down in October 2000.

[5] Stepped down before the next GA.

25 May 2008
(GA election, Vienna)
– 22 May 2009
Wim Vandevelde, Portugal, chair; Alain Volny-Anne, France, secretary; Smiljka de Lussigny, Serbia; Stefan Stojanovik, Macedonia, treasurer; Thandi Haruperi, UK

22 May 2009
(GA election, Brussels)
– 30 May 2010
Anna Żakowicz, Lithuania, chair; Stefan Stojanovik, Macedonia, treasurer; Thandi Haruperi, UK, secretary[6]; Alain Volny-Anne, France; Luis Mendão, Portugal, vice chair

30 May 2010
(GA election, Frankfurt)
– 11 September 2011
Anna Żakowicz, Lithuania, chair; Stefan Stojanovik, Macedonia, treasurer; Luis Mendão, Portugal, vice chair; Alain Volny-Anne, France; David Haerry, Switzerland, secretary; Ferenc Bagyinszky, Hungary[7]

11 September 2011
(GA election, Berlin)
– 23 September 2012
Ferenc Bagyinszky, Hungary, chair; Stefan Stojanovik, Macedonia, treasurer; Brian West, UK, secretary

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[6] Left the BoD in September and replaced as secretary by Alain Volny-Anne.

[7] Became secretary starting 1 May 2011.


COPY=RIGHT

ACRONYMS

BoD
Board of Directors

CAB
community advisory board

COPE
Continuous Patient Education Project

ECAB
European Community Advisory Board

DG
Directorate General for; directorate general *(European Commission)*

DG Sanco
Directorate General for Health and Consumers *(and previously, Directorate General for Health and Consumer Protection)*

EGA
Extraordinary General Assembly

EMA *(previously **EMEA**)*
European Medicines Agency

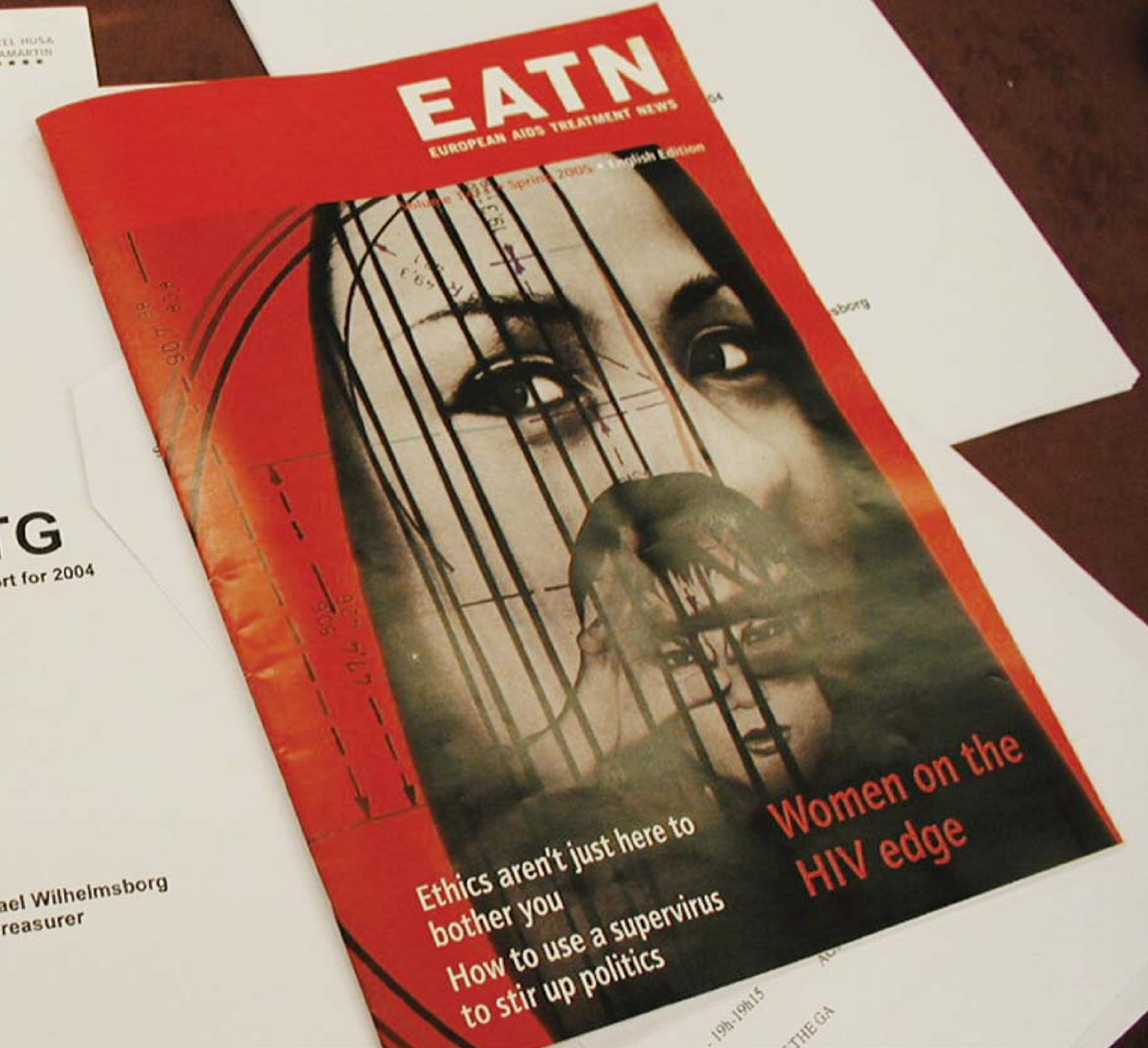
EUROPRISE
European Vaccines and Microbicides Enterprise

GA
General Assembly

GIPA Principle
Greater Involvement of People Living with [or Affected by] HIV/AIDS Principle

GNP+
Global Network of People Living with HIV/AIDS

MEP
member of European Parliament



EATN

EUROPEAN AIDS TREATMENT NEWS

Spring 2005 • English Edition

Women on the HIV edge

Ethics aren't just here to bother you

How to use a supervirus to stir up politics

TG

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“Carry on,
EATG,
bringing
passion
to pills.”

—Lisa Power, 2012 stakeholder meeting

The EATG would like to thank its members, partners, sponsors, networks, supporters and all the other people who contributed to its work during all these years.

To mark the 20th anniversary of the European AIDS Treatment Group and to frame the debate for the decade to come, this festschrift begins with an account of the organisation from its founding to the present day. Descriptions of some major initiatives follow, along with personal accounts by members and former members of past work and future challenges – including not-always-reverent recollections of memorable moments from the EATG's first 20 years.

EA
TG

European
AIDS Treatment
Group

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

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