

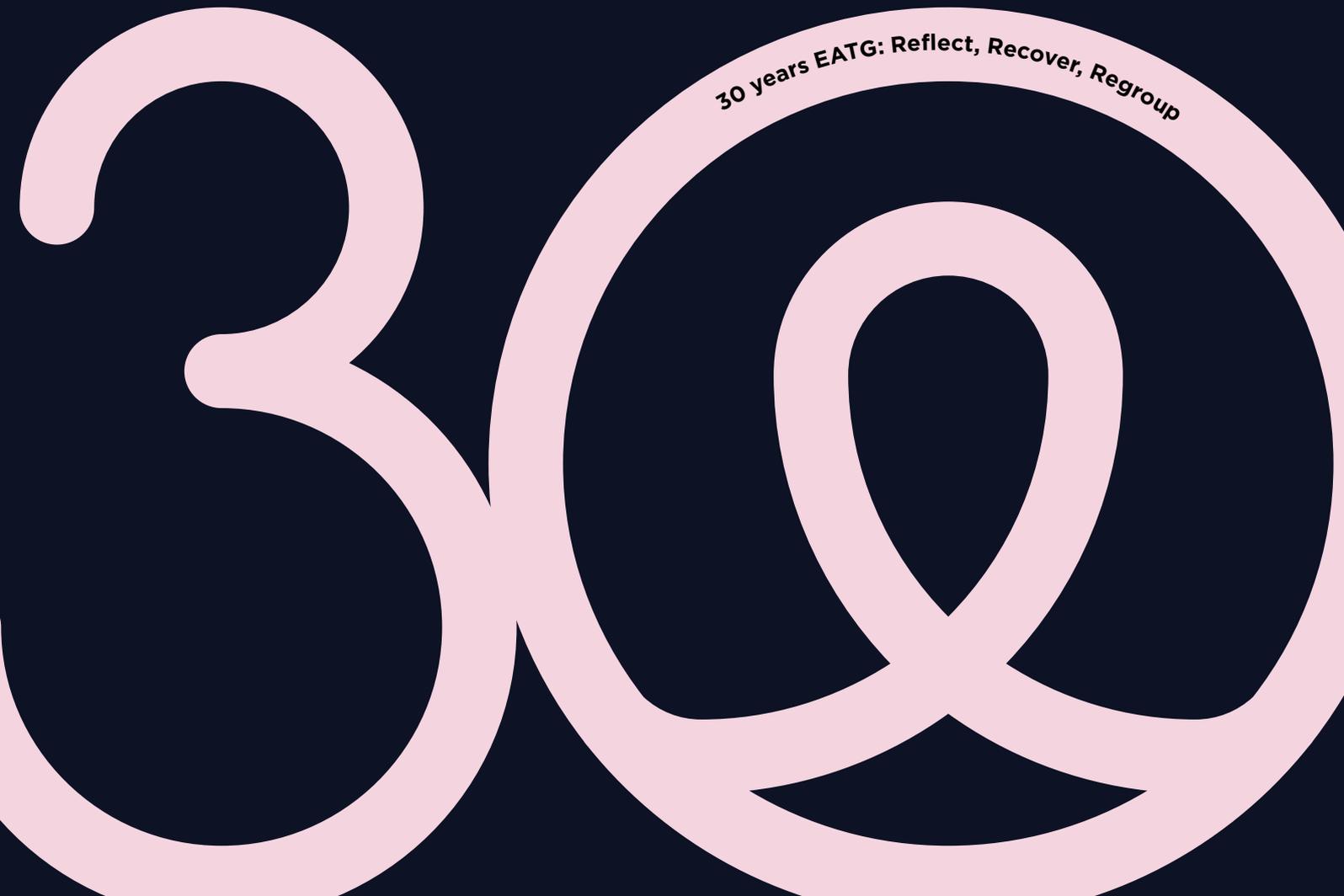
30
YEARS

EATG

European
AIDS Treatment
Group

CELEBRATING 30 YEARS OF HIV ACTIVISM: STORIES FROM THE FRONTLINE

30 years EATG: Reflect, Recover, Regroup



CELEBRATING 30 YEARS OF HIV ACTIVISM: STORIES FROM THE FRONTLINE

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Ian Hodgson
COORDINATION & EDITING

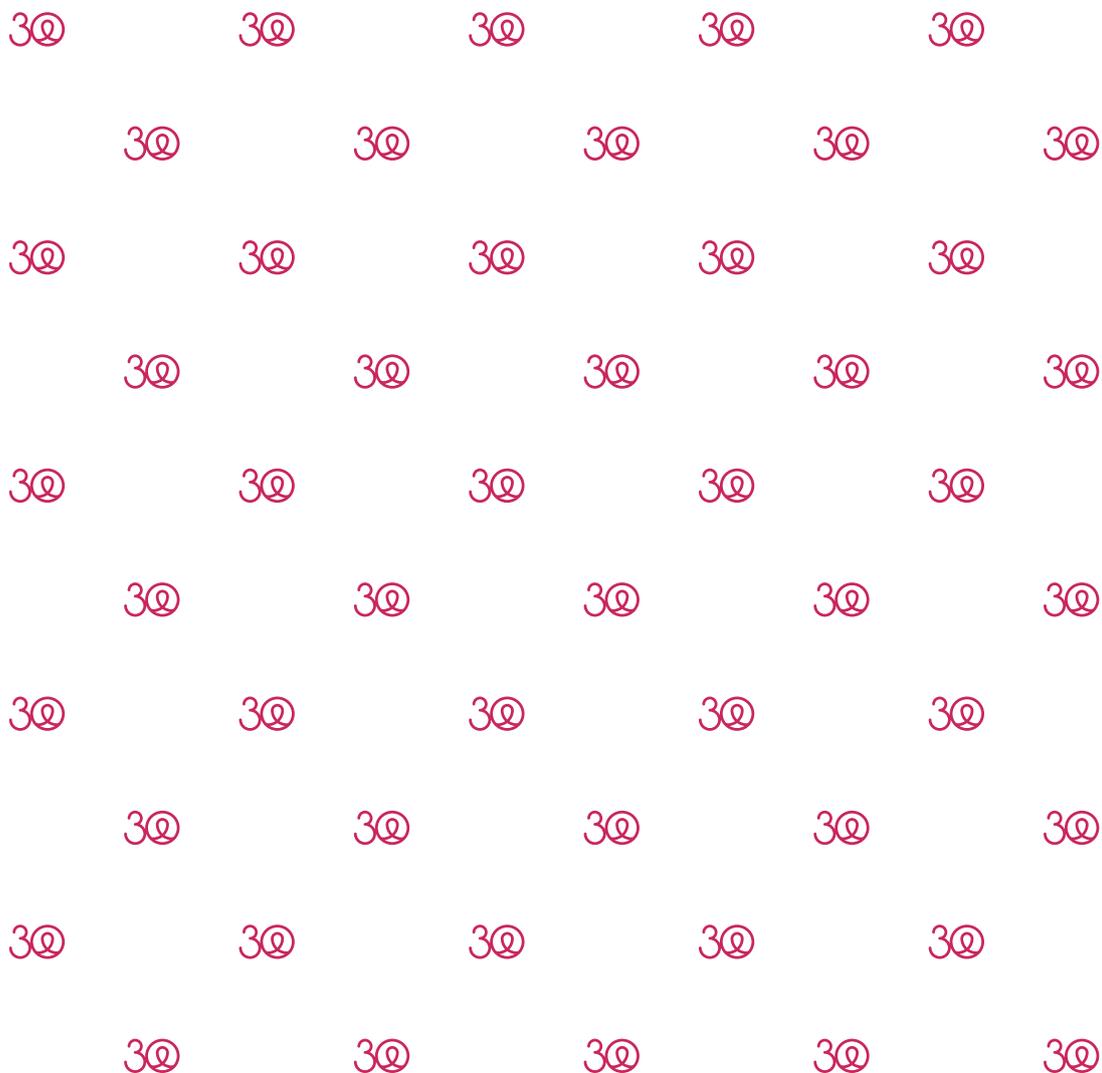
Apostolos Kalogiannis
EDITOR-IN-CHIEF

Dimitris Kanellopoulos @ Synthesee.com
LAYOUT DESIGN

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EATG would like to thank everyone who shared their stories for this publication. Their insights and honesty provide an important insight into the history of HIV and AIDS activism in Europe over the last 30 years, not only by EATG but the many other people and organisations fighting for justice and the rights of affected people and communities over the years.



FOREWORD

BY RICARDO FERNANDES
BOARD OF DIRECTORS | CHAIR





Over its 30 years, EATG has grown to become a Europe-wide organisation of people living with or affected by HIV coming from the most affected communities and areas. It is also, despite being mature, in a constant state of renewal.

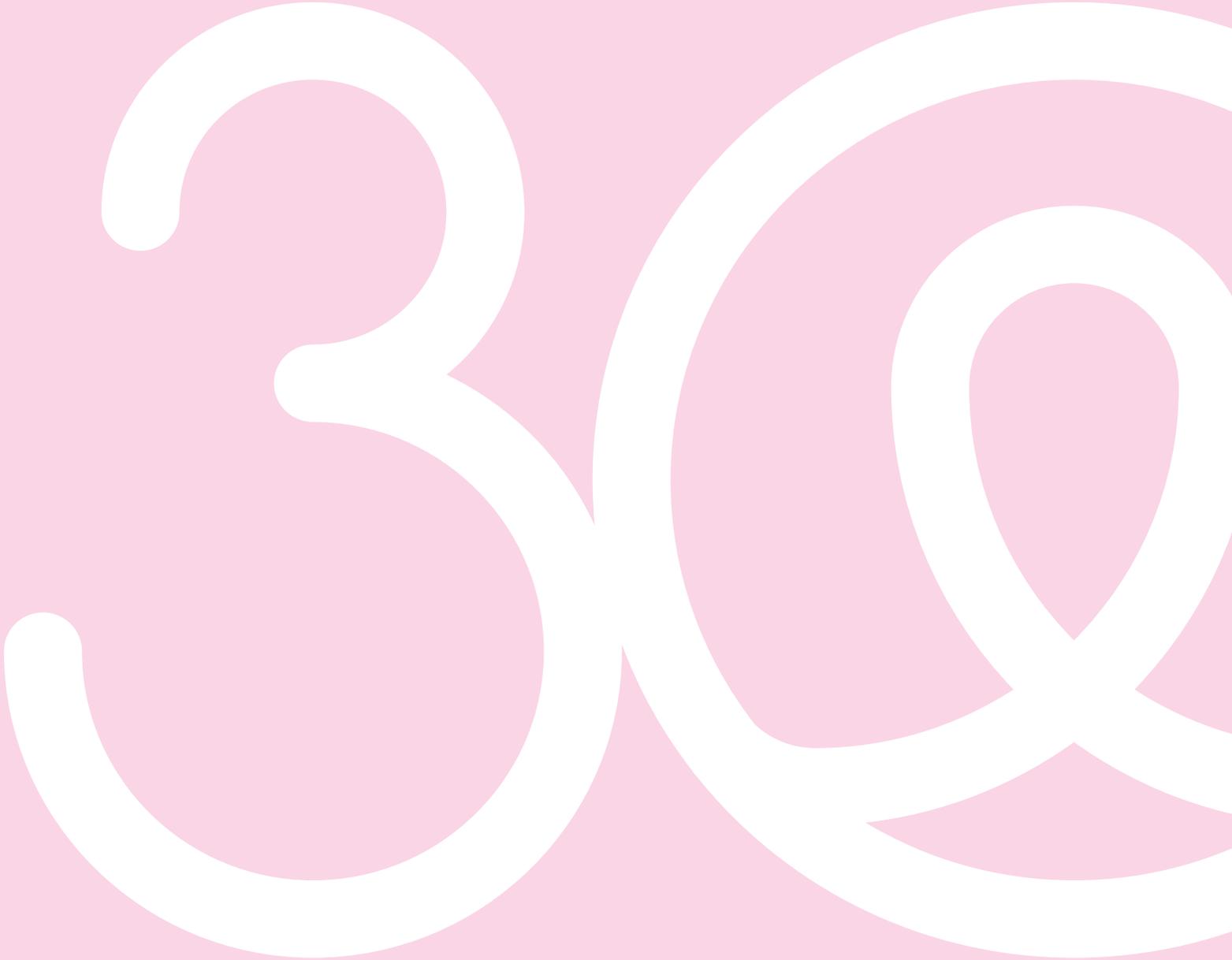
Those familiar with the work and history of EATG know that its contribution to changing the landscape of HIV and communicable diseases in Europe, and perhaps the world, is undeniable. Looking back over the last 30 years allows us to reflect on our journey, on the organisation we were and are, and think about our successes and failures with the generosity and frankness that have always characterised EATG.

Over these years there have been many losses: of people important and dear, and of some of the battles we fought. Mistakes have been made and lessons learned, which is part of being human and genuinely from the community. The HIV epidemic has been devastating for our community and remains so in some areas. Other recent epidemics, such as COVID-19 and monkeypox, aggravated this and demonstrated how stigma and discrimination still need to be addressed. Other structural problems remain as barriers to achieving the goals we all set ourselves: ending HIV and viral hepatitis as a public health problem.

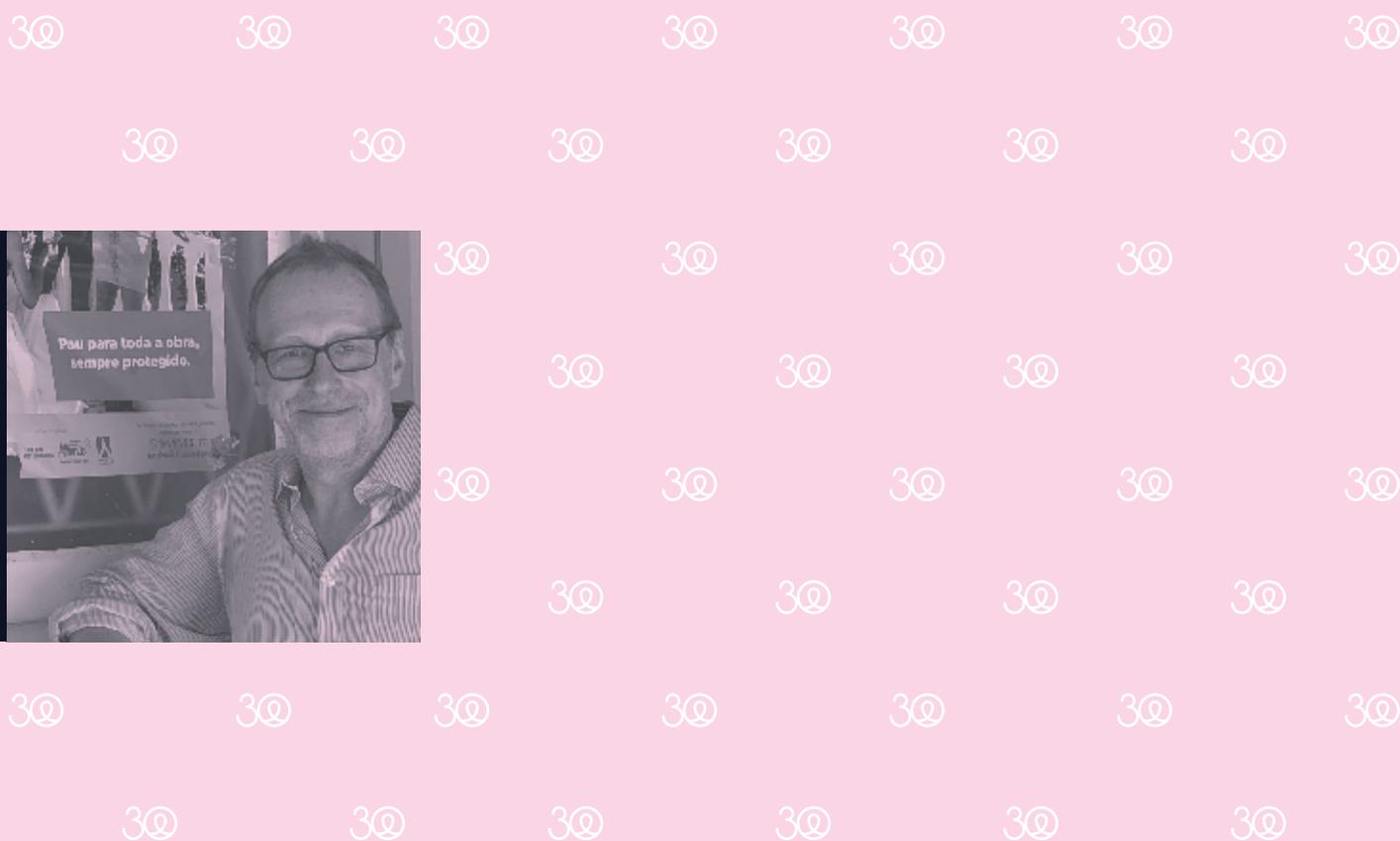
This is why we need to regroup and come together in a big, empowering hug that allows us to recover. We need to regain strength, align strategies, reinvent ourselves, and move on to whatever challenges we may face in the next 30 years.

I therefore invite you to read these stories. They include accounts of activism pioneers who fought to save their lives and those of their loved ones. Some are narratives from people who recently joined our ranks, others from members present at the very beginning of EATG who, 30 years later, still feel the need to be part of an organisation serving the most disadvantaged communities. It is an intimate moment that we want to share.

Join us in this moment as we reflect recover regroup. Good reading.



CELEBRATING 30 YEARS OF HIV ACTIVISM BY IAN HODGSON





The year of EATG's launch, 1992, feels like another age. Thirty years ago, the world of HIV in Europe was very different. Care was medicalised, and treatments toxic and often poorly tolerated. AIDS mortality was high (in the US, the leading cause of death for men aged 25-44), and the patient's voice severely muted. Stigma was rife and heavily politicised, fed by a poor understanding of HIV, conservative religious views, and general abhorrence against lifestyles seen as 'inappropriate'. The moral panic towards AIDS, born in the 1980s, was still strong.

It was in this maelstrom that plans were made in 1991 between the UK's Terence Higgins Trust and Deutsche AIDS-Hilfe to hold the first AIDS & Medication meeting, specifically for AIDS activists, to strategise treatment activism in the European context. From that meeting came the first European AIDS Treatment Agenda, in time for the 7th International AIDS Conference in 1991, and the first statement of its kind. In the following year, 1992, the AIDS & Medication meeting was held in Berlin, attended by 19 people from nine European countries and observers from the EC and WHO Europe. It was here that the European AIDS Treatment Group was formed and registered in Germany (which it is to this day).

Now, in 2022, EATG remains one of the only member-led organisations of its kind in the European region, and as such can give a face to HIV in Europe. As an organisation focusing on HIV, learning from the past evolving to address new issues and challenges is embedded in EATG's DNA, ensuring that patient and community voices aren't taken for granted.

EATG remains unique for two reasons. First, as a community and patient led organisation functioning at the European level, it provides a direct conduit for members to access European-level resources, and policy makers. Second, it is also able to react rapidly to significant events across the European HIV sector in ways that would be more difficult for 'umbrella' organisations. This was illustrated most recently in the case of COVID-19, where gathered and shared detailed information about the impact of the pandemic on HIV and related services, ensuring that information was accurate and current for members. Another is the ongoing (as in December 2022) conflict in Ukraine – here, EATG is liaising directly with HIV-facing NGOs in the country, providing technical support as needed.

EATG remains a volunteer, grassroots organisation that provides a level of vibrancy that is often characteristic of national organisations, but at a European level. It is made up of a tapestry of members from a wide range of backgrounds and levels of experience – some at the very beginning of their careers in the HIV sector and others at a highly advanced level with a significant depth of knowledge in science, training, and policy. One feature of EATG's work remaining constant through the entire 30 years is the European Community Advocacy Board (ECAB), where members interact directly with pharma to address urgent treatment issues, such as in 2022 speeding up access to injectable PrEP.

EATG has continually evolved and adapted over the years. A recent restructure of the organisation reflects EATG's response to shifting priorities around HIV and comorbidities, and emerging issues such as ageing with HIV and new approaches to HIV prevention. The three working groups – Partners in Science, Quality of Life, and Combination Prevention – represent the wide-ranging approach required to contribute towards ending AIDS by 2030.

EATG would be nothing without its members. Throughout the last 30 years their commitment, resilience, passion, and constructive scepticism remain at EATG's core, and impelling us forward to meet new challenges. Some member contributions are included on the following pages, which include memories and stories from each decade of EATG's lifespan. We hope the stories you read demonstrate EATG's capacity to reflect, recover, and regroup. We also hope that you find the contributions interesting, informative, uplifting and thought provoking as you think about EATG entering its fourth decade, during which we expect AIDS to become a thing of the past.

A brief history of EATG



MAXIME
1996 | FRANCE



PAGE 22

FILIPPO
1997 | ITALY



PAGE 26

ALAIN
1997 | FRANCE



PAGE 30

THE 1990s

At the beginning of the decade, the deaths of several 'noted' people, for example Ian Charleson and Freddie Mercury in the UK, and Ryan White and Arthur Ashe in the US, significantly raised public awareness of HIV.



JENS
1998 | DENMARK



PAGE 34

KOEN
1998 | BELGIUM



PAGE 38

Treatment development focused on early versions of protease inhibitors which would prove later in the decade to be vital and effective against the development of AIDS when taken in combination with other antiretroviral treatments.

Treatment advocacy became increasingly radical and confrontational to increase access to the new treatments and was a reaction against what was perceived as unwillingness by pharma and politicians to accelerate their availability.

FERENC
2004 | GERMANY



PAGE 46

JEFFREY
2005 | SPAIN



PAGE 50

THE 2000s

Marked by a global push to make antiretroviral treatments as widely available as possible, especially in developing countries where HIV prevalence was skyrocketing.

Two new funding streams, the President's Emergency Plan for AIDS Relief (PEPFAR) launched by President George W Bush, and the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) were launched to speed up access not only to treatment but also HIV testing, an increasing global priority.

PAUL
2007 | UNITED KINGDOM



PAGE 54

DORTHE
2007 | DENMARK



PAGE 58

The 'Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia' (2004) galvanised responses to HIV and AIDS in the WHO European Region by promoting increased political focus on tackling HIV and AIDS and the priority on monitoring and evaluating actions implemented. It also emphasised the important role of civil society and people living with HIV in all areas of the response.

The 'Swiss Statement' (2008) announced that a person living with HIV, fully adherent to treatment and with an undetectable viral load, is essentially non-contagious. At the time this caused some controversy but is now the consensus view and a central component of the current U=U (undetectable=untransmissible) campaign.

BRYAN
2011 | FRANCE



PAGE 66

EDWIN
2012 | NETHERLANDS



PAGE 70

HARRIET
2014 | GERMANY



PAGE 76

MORGAN
2015 | UK



PAGE 80

THE 2010s

Continuing refinement of treatment and widening access to antiretrovirals and HIV testing. Increasing focus on comorbidities and addressing long-term challenges such as ageing with HIV and ensuring no-one is left behind in the HIV response.

DENIS
2016 | UK



PAGE 84

MAGDALENA
2017 | POLAND



PAGE 88

JACKIE
2017 | UK



PAGE 92

ANDRIY
2022 | UKRAINE



PAGE 96

Key milestones include international agendas now focusing on ending AIDS by 2030, and the folding of HIV into the broader agenda of sustainable development goals (SDGs).

Increasing attention to political, legal, and social factors continuing to obstruct advances in HIV prevention, such as anti-LGBT and drug legislation, stigma, and the exclusion of key groups such as sex workers and people who use drugs in national and international policymaking.



PAUL
2007 | UNITED KINGDOM



MORGAN
2015 | UK



DENIS
2016 | UK



EDWIN
2012 | NETHERLANDS



JACKIE
2017 | UK



KOEN
1998 | BELGIUM



MAXIME
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2022 | UKRAINE



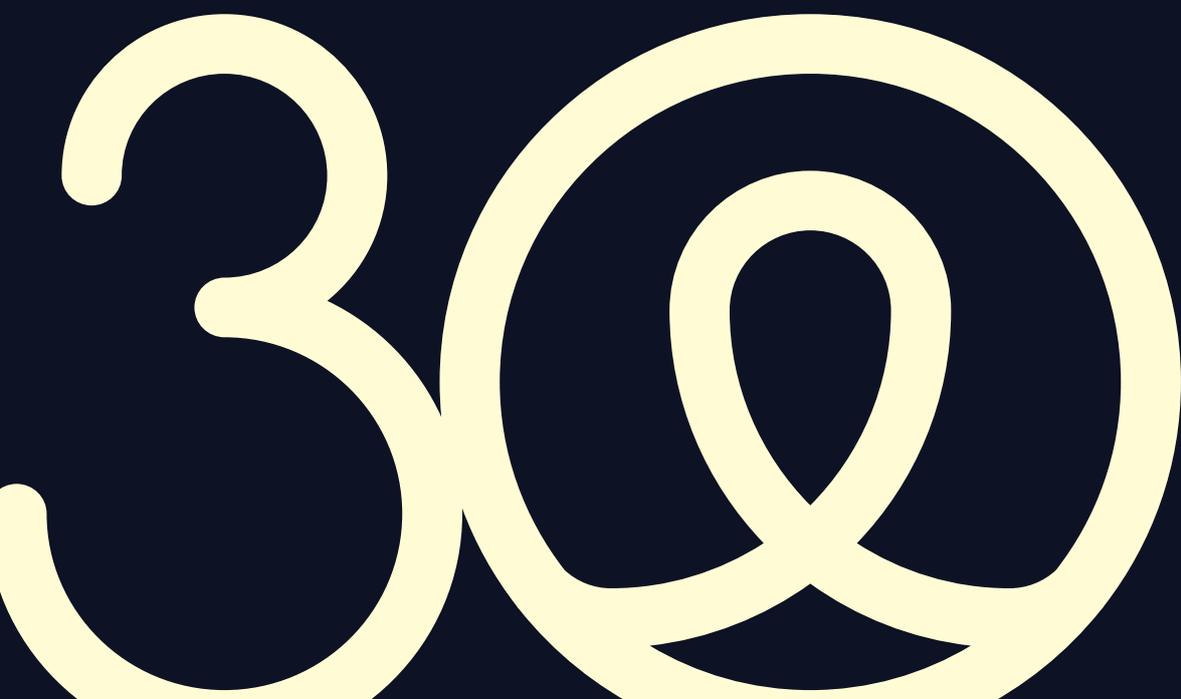
FILIPPO
1997 | ITALY

THE 1990s

MAXIME
1996 | FRANCE

FILIPPO
1997 | ITALY

ALAIN
1997 | FRANCE



JENS
1998 | DENMARK

KOEN
1998 | BELGIUM

**EATG AND HIV ACTIVISM:
THE VIEW FROM FRANCE IN FRANCE**
MAXIME JOURNIAC

THE WAY WE WERE
FILIPPO VON SCHLOESSER

SUBTLE ACHIEVEMENTS CAN BE GAME CHANGERS
ALAIN VOLNY ANNE

A DANISH ACTIVIST AT EATG
JENS WILHELMSBORG

AMPLIFYING THE COMMUNITY VOICE
KOEN BLOCK

1996

FRANCE

The 1990s

22

**EATG AND HIV
ACTIVISM:
THE VIEW
FROM FRANCE
IN FRANCE**

30
YEARS

Maxime Journiac



Former EATG member

I am a 68-year-old, retired French gay man living in Paris. I was a member of EATG from 1996 until 2017. I have been living with HIV and other co-infections for 40 years. I have been an HIV-AIDS activist for 35 years, first in New York in the late 80s with ACT-UP, then in France from 1992 until 2008 as part of TRT-5 (a collaborative collective of French HIV/AIDS NGOs which is also celebrating its 30th anniversary), and then at the European level within EATG. I stopped my activism for health reasons and great fatigue.

To me, one of the best of EATG achievements was, and probably still is, the capacity of the group to welcome, support, and empower new members via conferences, publications, and training.

I remember all the regional conferences EATG organised, such as the Southern States conferences (Spain, Portugal, Italy, and Greece), the South-eastern and Balkan conference (Bulgaria, Romania, and all the republics of former Yugoslavia), and the Eastern European conference (Russia, Ukraine, and some other former Soviet republics).

There was also the publication of information fact sheets in national languages (for example in Spanish, Italian, Portuguese, Czech, Polish, Hungarian, Romanian, Bulgarian, Serbo-Croatian, and Russian). A daily newsletter that gathered information on current updates on HIV and AIDS was also helpful.

I am very proud to have been part of that on-going fight against HIV/AIDS, where I learned that it is within such groups as EATG that a collective intelligence can emerge to make a difference in the lives of hundreds of thousands of people living with HIV/AIDS throughout Europe.

Then there was the European Community Advisory Board (ECAB), of which I was a member. This was, in my opinion, the best school to acquire scientific knowledge, negotiation skills, and critical arguments to face the pharma Industry.

There were also international conferences members attended, often with the help of EATG. I mainly think of the bi-annual Glasgow conference which was one the best accessible conferences for a non-scientific audience to learn about the State of the Art in terms of new treatments and therapeutic strategies.

The most exhilarating moments for me were when I witnessed the emergence and the blossoming of new members. They were shy and quiet at first, then became brilliant, articulate, and powerful members, active both at the national level European levels.

Often, new members, through their newly acquired skills, have been able to change HIV policies in their countries, solving problems around access to treatments and changing the relationship of communities with policy makers and health authorities.

Equally, when they could not access local pharma representatives, unaccustomed to deal with HIV activists that they regarded as intruders and illegitimate interlocutors, the problem was often solved by addressing their query directly to the European and even US headquarters who were the people we were meeting at the ECAB.

I will finish by saying that I am very proud to have been part of that on-going fight against HIV/AIDS, where I learned that it is within such groups as EATG that a collective intelligence can emerge to make a difference in the lives of hundreds of thousands of affected people throughout Europe.

My final message goes to all the members. I am sure they have at heart the determination to keep alive the rightful fight for better treatments, treatment access, and a strong solidarity against inequalities and discrimination.

I wish them all the best successes in the achievement of their projects.

I'd like also to remind them to keep in mind the famous phrase of the Denver declaration that states: "Nothing about us without us."

1997

ITALY

The 1990s

26

THE WAY WE WERE



30
YEARS

Filippo von Schloesser



EATG member

NADIR ETS

Thirty years ago, a star is born in Berlin. A group of HIV activists had formed a nascent group that aimed to address pan-European inadequacies in awareness, treatment access, and the involvement of people in the first pandemic during which I lived: the HIV/AIDS pandemic.

In my constant and restless research to not leave the virus to do its job on my body, I tried to be an Italian treatment activist, but I remained unheard for a long time until two guys, Raffi Babakanian and François Houyez, both members of EATG and on the BoD, were looking for an Italian member living with HIV. They found me and asked if I could be of some help.

Never has an invitation made me happier. My first meeting was the London General Assembly in 1997, and a few months later the Helsinki AIDS and Medication meeting, a fantastic training workshop that made me dive into the pool where I wanted to swim for the rest of what I thought it would be my short life dominated by AZT, TB, and meds. It was also the year triple combination therapy was launched to the world.

At that time, conflicts appeared in the management and decision-making of communities, such as putting together people from countries with and without access to treatment, and from diverse traditions and cultures with very different perspective. We used to tell each other, "Remember, we have to fight a virus, not our friends." The genius of this amazing, pioneer, rather hidden group of mad people who wanted to survive HIV brought several good and valid projects,

In my constant and restless research to not leave the virus to do its job on my body, I tried to be an Italian treatment activist, but I remained unheard for a long time until two board members of EATG were looking for an Italian member living with HIV. They found me and asked if I could be of some help. Never has an invitation made me happier.

such as the European Community Advisory Group (ECAB). It did take a long time to understand the way we wanted to create and run a valid and homogeneous group to interface and overcome those monsters that at that time we considered the enemy: Big Pharma, that manipulated timing, pricing, information on blood concentration and interactions, and access to treatment for people in real need.

In 1998 I heard the words 'mitochondrial toxicity' and 'lipodystrophy' for the first time in my life. I looked at my colleagues and found they were living the same drama that would psychologically harm us forever.

I started hating pharma manipulation, though my message to my EATG colleagues, which was a time when Act Up was still active was only to Negotiate, Negotiate, Negotiate! The fight for Fuzeon and its pricing started in 1999 and cost the manufacturer more than 6 months delay to enter the market.

We created the Southern States Conference (SSC), organized every year either in Spain, Italy, Portugal, or Greece, as we felt a huge lack of awareness was

dividing Europe into two sides, above and below the Alps. From the year 2000 we launched the Eastern State Conference to bring our struggles to Russia, the Czech Republic, Slovakia, and Hungary. Of great help to put together a group of HIV Eastern people was MSF who had recently won the Nobel Prize for peace.

In 1997, EATG's General Assembly decided to elect me member of the BoD at the Rotterdam meeting, the same day Princess Diana died. Few months later, after Arjien Broekhuizen was injured in an accident who would jeopardize his weak health (he died in 1999, after suffering what we all had tried to prevent), Ana Souza Passos decided to step down, so the BoD elected me BoD Chair in Athens. François, Rob Camp, Nikos Dedes, and Tytti Poutanen from Finland helped me quite intensively, until 2003 where, at the General Assembly in Budapest, I stepped down.

We were a very integrated group of people. We interchanged a lot of information as a source of inspiration to create new projects and fight for better long term-outcomes. We were in a constant, never-ending meeting thanks to a new tool: e-mail.

Our first mission to Moscow, in 2001, was unforgettable. The person running EATG's Düsseldorf office, Alain Willgerodt, was jailed for a month due to a mistake in a Ruble declaration checking out at Moscow airport. It cost us incredible diplomatic and legal effort to have him back home. We decided to move to Brussels in 2002 as the EU was enlarging and relying on our help at a time where internet was not a common tool.

I still feel linked to those members who dared to survive, like me, and for the help you gave me, you who are still fighting for our health for many years and in many countries.

1997

FRANCE

The 1990s

30

**SUBTLE
ACHIEVEMENTS
CAN BE
GAME
CHANGERS**

30
YEARS

Alain Volny Anne



EATG member

When I joined the EATG in 1997, it was natural for me to also join its European Community Advisory Board (ECAB). This was because, for years, I had already been engaged in Act Up-Paris' activities around HIV research and treatment, and in a similar role in TrT-5 meetings (the French Community Advisory Board).

One of our goals in ECAB was (and still is) to make sure that clinical HIV research does not happen without the involvement of the people it is meant to serve. Nothing without us, remember? So, we trained on specific medical topics - knowledge = power - and interacted with researchers around research ethics, regulations, needs, and clinical trial designs.

It took us years to establish a relationship with researchers based on trust, particularly those working in pharmaceutical companies. To say that it was not easy would be a gross understatement. It was hugely difficult. But we had done it.

However, we soon realised that something was missing. We were regularly invited to clinical trials investigators' meetings, scientific conferences, and other fora where our views would be heard. We visited the labs where research was happening. Fine, but what about us having access to clinical trial protocols, and commenting on them, as well as other relevant documents such as the patient information sheet before - not after, right? - the trial starts? After all, this material would determine the day-to-day lives of people we are meant to support, even people we may know personally...

ECAB's involvement in protocol reviews has been in place for some time and is running smoothly. The company has expressed its satisfaction several times. They and we understand a 'pre-reviewed by community' label on a registrational dossier is of great added value for the company. But then, why not, if it means their trials have become more friendly to participants?

I remember the embarrassed looks on faces, the grins, and bland comments such as, 'We will make sure that your feedback is communicated to our clinical trial development team'.

We did not give up. We expressed frustration, we reiterated, and here we are now, reviewing clinical trial protocols and enjoying this major achievement.

There was some kind of turning point in 2017-18, when one of the pharmaceutical companies with which we regularly interact approached us to discuss a new protocol review method they wanted to introduce, where we – the community – could intervene before any draft protocol submission to the FDA. A specific team of ECAB reviewers would receive a pre-draft and send comments and suggestions which would be incorporated into a second draft. If our comments weren't included, we would receive written feedback saying why. This was totally new!

Since then, this process has been in place and is running smoothly. The company has expressed its satisfaction several times. They and we understand a 'pre-reviewed by community' label on a registrational dossier is of great added value for the company. But then, why not, if it means their trials have become more friendly to participants?

Another activity we thought important was creating more readable versions of the language in documents provided to them by investigators. We questioned complex procedures - is that really necessary? - and reworked eligibility criteria that were obsolete and discriminated against many people. We pushed for a greater diversification of trial participants to include women, transgender people, and drug users. We demanded that trial participants be informed of trial results ahead of the general public, sometimes with success. We are perfectly aware of not being 100% successful, but we never give up.

All these achievements may all look quite subtle to some. But sometimes, subtle achievements are game changers.

1997

DENMARK

The 1990s

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**A DANISH
ACTIVIST
AT EATG**

30
YEARS

Jens Wilhelmsborg



EATG member
HIV-Denmark

As a Danish HIV activist for almost 30 years, it's time to reflect on the significance of being an EATG member and the advantages it has made available to my voluntary work for the HIV community in Denmark.

First, let me introduce myself. My name is Jens Wilhelmsborg, and I was diagnosed with HIV in the early 1990s. After accepting my positive situation, which took some time as the prediction for a long life was a bet with no closing stages, I decided to involve myself with the Danish HIV community in 1993. This was in the hope to be able to support, assist and help the HIV-positive persons anywhere in the community. It was the best decision I ever made; to be able to reach out to HIV-infected persons and at the same time become member of HIV-Denmark.

Early in my membership, I realised that most of the members in the organisation were focusing on the well-being of HIV-positive people and not much on treatment possibilities, which at that time was extremely limited. Regardless, the medications aspect interested me a lot, and I started to investigate pharmaceutical companies for news concerning research for HIV medications.

We are now in 1998 and a medical conference for HIV-focused NGOs was held in Warsaw. HIV-Denmark decided that two members should attend, and I was chosen as one of the two. It was my first HIV conference, and I was excited to learn more about treatment options and to bring the new data back to the Danish HIV community. Everything was overwhelming, but one

I went to EATG's lecture in 1998 and was impressed with the organisation and members who spoke. I was overwhelmed by the exceptional presentations. So much so that, when I got back to Copenhagen, I contacted the EATG office in Düsseldorf to apply for membership.

presentation in the programme got my attention; It was EATG sharing information about their organisation and at the same time giving me the opportunity to spend time with other activists from Europe in a small roundtable setting.

I went to EATG's lecture and was impressed with the organisation and members who spoke. I was overwhelmed by the exceptional presentations. So much so that, when I got back to Copenhagen, I contacted the EATG office in Düsseldorf to apply for membership. The office was helpful and pointed out that the organisation didn't have any members from Denmark. After a few weeks, I was contacted by the Office manager Dieter Schellschmidt who invited me to a meeting of EATG's European Community Advisory Group (ECAB) meeting in Lisbon, He explained that it would give me the opportunity to meet other members. I accepted the kind invitation to attend, and after the meeting I was certain that I needed to become an EATG member. HIV-Denmark backed my idea and convinced me to apply for membership. I applied and was accepted.

In 2000 I attended the first General Assembly and was elected to be a board member, becoming treasurer at the constitution meeting.

The office at that time was in a small single storey house in Düsseldorf, Germany. A nice comfortable little house for three employees: The Office manager, a secretary, and a young office assistant taking care of all ECAB matters. As EATG activities expanded, and the organisation needed to enlarge the office space.

Many of our donors (pharmaceutical companies) had complained that Düsseldorf was a difficult city to reach for meetings. The Board began to look for properties outside Germany, and Brussels came up repeatedly. Especially because of the location of the EU's Headquarters. EATG hoped with the move that the organisation would be more visible on the international scene for HIV activism.

The EATG office in Düsseldorf was closed and moved to Brussels, Belgium which has proven to be an intelligent decision.

For me the EATG membership has been and still is an important part of my activism for the Danish HIV community, especially my ECAB participation. Here, I have gained knowledge about new compounds for HIV treatment, which has given me the opportunity to bring that new wisdom of HIV-treatments back to Denmark for the benefit of the HIV-community.

I have succeeded in helping many HIV patients in Denmark gain knowledge about and access to new medicines.

I cherish my membership of EATG, which has kept me updated on new developments of HIV medicine for nearly 23 years.

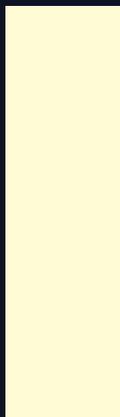
1998

BELGIUM

The 1990s

38

AMPLIFYING THE COMMUNITY VOICE



30
YEARS

Koen Block



EATG member & former
Executive Director

Since I joined the European AIDS Treatment Group (EATG) in the second half of the nineties, the role of EATG has been crucial, not only for my personal development through training sessions but also as a link between the local and European level. For example, work within the European Community Advisory Board (ECAB) has directly contributed to increased access across the region to crucial treatment through trials and access programmes in a period when treatment was not widely available.

The voices of the community and their role in moving scientific research, access, acceptability, and solidarity forward can never be overestimated. As a member, and later as director, I have seen growth in EATG's membership and its coverage of additional countries, regions, and research areas. EATG also played an important role in making affected communities more visible in meetings, bringing their needs higher on the agenda of researchers and companies. Women's involvement has also increased through the years, as well as representation from people who use drugs, LGBTIQ+, sex workers, and ethnic minorities within Europe and Central Asia.

In addition to HIV treatments, EATG quickly adopted a broader scope to include HIV comorbidities, co-infections, and vaccine development. This included improved HIV prevention, and EATG fully adopted the recent U=U campaign. Again, the voices of the community followed these evolutions and working groups were set up to allow in-depth focus and discussions.

It is a pleasure to see that, after so many years, EATG has not lost that critical and activist vision. This is demonstrated by its rapid response to community needs identified during the recent Covid-19 crisis.

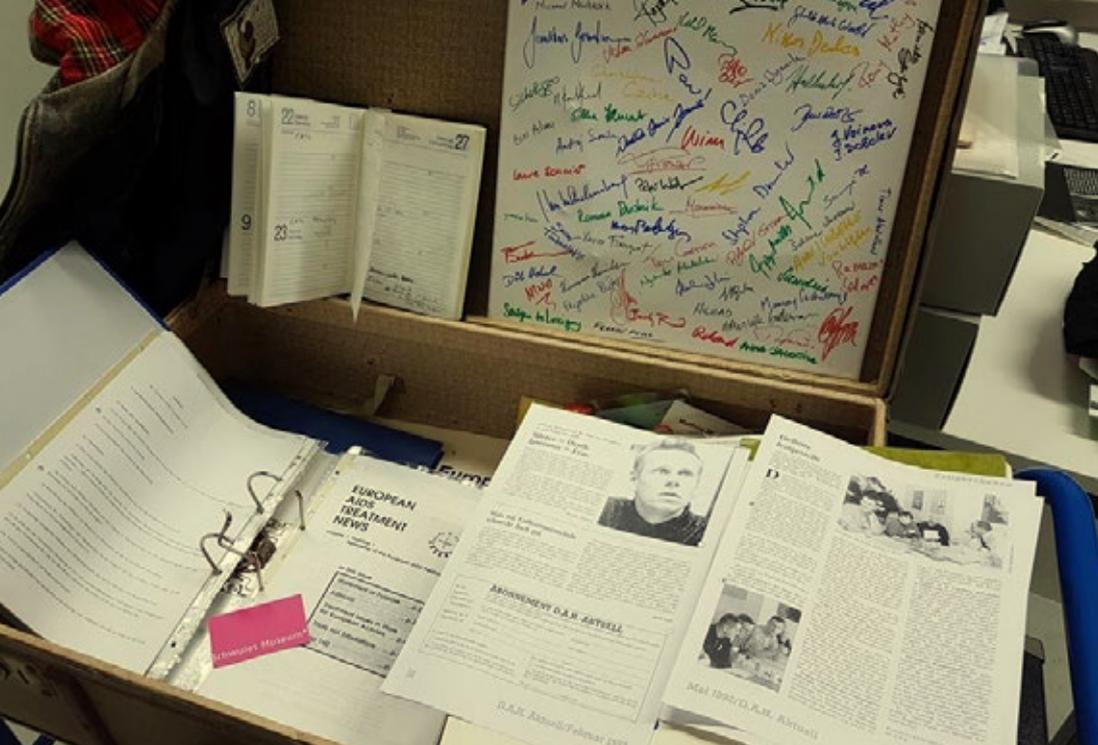
EATG members became increasingly involved in projects as highly valued community experts, with focus on both clinical and social science. Bringing a patient focus into research has been a key factor in EATG's success. The importance of patient involvement came at the height of the EUPATI project, that was directly focused on patient education and their inclusion as experts.

EATG trained many people through its capacity building projects, such as COPE or the STEP-UP programme, and directly supported the inclusion of more people at all levels of community involvement, making it meaningful and effective. Patient experts have been able to convince researchers, health care providers and pharmaceutical companies of the mutual benefit of dialogue at all levels and through all stages and is increasingly seen as good practice.

The community response to HIV/AIDS has been a pilot and example for many disease areas and the model of community advisory boards an inspiration to other international and local advisory boards.

It is a pleasure to see that, after so many years, EATG has not lost that critical and activist vision. This is demonstrated by its rapid response to community needs identified during the recent Covid-19 crisis. New members keep on joining with diverse backgrounds, knowledge, and skills. The success of EATG lies within its membership. Drawing on community voices to improve people's wellbeing is in its DNA.

I am proud to have been part of that history and hope that EATG will be able to continue fulfilling its crucial role as long as it is needed in the coming years.

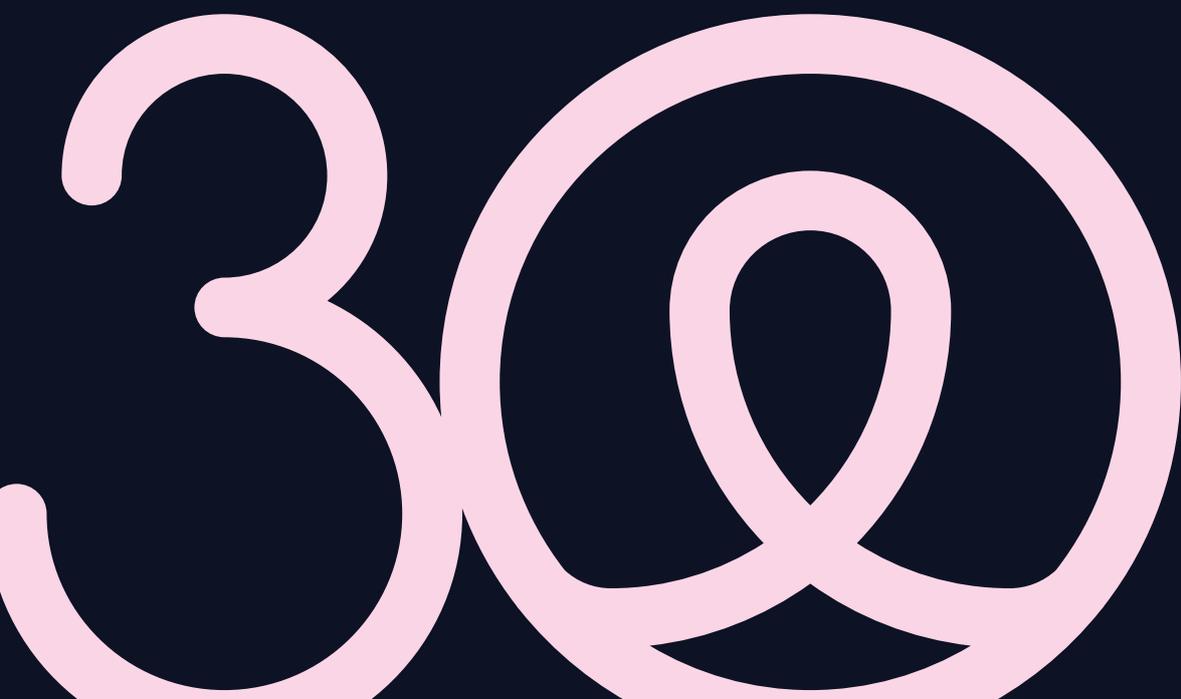




THE 2000s

FERENC
2004 | GERMANY

JEFFREY
2005 | SPAIN



PAUL
2007 | UNITED KINGDOM

DORTHE
2007 | DENMARK

EUROPEAN PARTNERSHIPS, RESILIENCE,
AND LOOKING TO THE FUTURE
FERENC BAGYINSZKY

CIVIL SOCIETY'S ROLE
IN THE HIV RESPONSE:
WHY EATG IS CRUCIAL
JEFFREY V LAZARUS

EATG AND THE POWER OF ECAB
PAUL CLIFT

EATG'S CONTRIBUTION
TO EUROPEAN-WIDE
HIV TESTING INITIATIVES
DORTHE RABEN

2004

GERMANY

The 2000s

46

EUROPEAN PARTNERSHIPS, RESILIENCE, AND LOOKING TO THE FUTURE

30
YEARS

Ferenc Bagyinszky



Former EATG member
AIDS Action Europe

Happy 30th Anniversary dear EATG friends and colleagues!

The European AIDS Treatment Group (EATG) has been one of our key strategic partners in European HIV policy and advocacy since the establishment of our network – AIDS Action Europe – back in 2004. Following the Dublin Declaration on Partnership to fight HIV/AIDS in Europe and Central Asia, we could together enjoy the ‘heyday’ of HIV policy development and relatively high awareness of HIV and other communicable diseases.

Unfortunately, this interest gradually waned in the last decade as European priorities shifted towards security and emergency issues. The space for civil society has shrunk and, in many cases our, ‘seats at the table’ were questioned. A very strong example of this growing lack of interest was the European Commission’s decision to close the EU HIV/AIDS, TB and Viral Hepatitis Civil Society Forum, an important advisory body to the Commission and co-chaired by EATG and AAE since its establishment in 2005.

EATG, as a pan-European patient-led network, has played a unique role in the region by representing and working for the interest of people living with HIV and other key affected populations.

However, communities and the broader civil society have always been resilient, and we are known for our ability to adapt and think outside the box. A prime example of this was the relaunch of the Civil Society Forum as a self-managed and self-organised network. The forum will continue the previous forum's tradition to provide opportunities for an exchange of knowledge and knowhow, advocate for the rights of communities living or affected by these infections, contribute to the empowerment of community groups, and participate in European level policy and programme development.

EATG, as a pan-European patient-led network, has played a unique role in the region by representing and working for the interest of people living with HIV and other key affected populations. On the 30th anniversary of your continued advocacy, HIV policy and science work, I would like to encourage you to stay resilient and strategic in your thinking, looking for new perspectives in our ever-challenging policy landscape and in the face of the continued challenges that we have been seeing in the last years. Most importantly of all, I would like to encourage you to be proactive in your role of shaping the next decade of HIV and co-infection advocacy in the region.

On behalf of the AIDS Action Europe Office and the Steering Committee, I would like to congratulate you on your 30th anniversary and we look forward to continuing our cooperation in the future!

2005

SPAIN

The 2000s

50

CIVIL SOCIETY'S ROLE IN THE HIV RESPONSE: WHY EATG IS CRUCIAL

30
YEARS

Jeffrey V Lazarus



ISGlobal

HIV Outcomes

In 2005, when I joined the World Health Organization's HIV programme, it was obvious that civil society engagement would be the key to ending AIDS. And in Europe, that meant engaging with EATG. Having no mobile phone at the time (I was the last in my office without one), I fired off an email to the Secretariat instead. They got back to me, and soon enough I was connected with the then-chair of the board, Nikos Dedes. Now, after more than 15 years, I'm proud to recognise that the partnership – and friendship – with him and others at the EATG remains solid.

What would occur over just a few years would transform HIV prevention, treatment, and care in Europe and around the world, mainly thanks to the EATG-WHO Europe partnership and the stewardship of the then-regional adviser, Srdan Matic (also my boss). For instance, WHO Europe and EATG signed an MoU in 2005 to formalise the collaboration. We then organised the first major meeting with the community just months later. More than 100 representatives engaged with WHO staff from across the continent to determine what next steps to implement. We shared memorable experiences at the Berlin Film Hotel and watched *And the Band Played On* in the evening.

Afterward, with extensive support from the EATG, we published a book on the history of HIV in Europe and issued a landmark report, 'Progress on Implementing the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia'. The Dublin report (300 pages!) does well to capture the importance of the collaboration:

Looking ahead to the horizon, the EATG has shown that it will continue steadfast in its mission. Not only is it leading the way in HIV and many co-infections, but it has already stepped up to confront the most recent challenge of multimorbidity.

“Especially noteworthy was the Planning and Technical Consultation on Working with Civil Society to Scale up Access to HIV Prevention, Treatment and Care, held in Berlin in October 2005... For the past three years, the WHO Regional Office for Europe has employed a community advocate on the staff of its HIV/AIDS programme, whose many responsibilities have included organizing the Berlin technical consultation in conjunction with the European AIDS Treatment Group.”

In 2009, I left WHO and went to the Global Fund. When I got back to Denmark to help found the WHO Collaboration Centre on HIV and Viral Hepatitis, the EATG asked me to write their 20-year anniversary book. This is a snippet from the invitation letter sent out:

“Misha Hoekstra and I are preparing a publication for the European AIDS Treatment Group and would very much like your input. To mark the 20th anniversary of the EATG and to frame the debate for the decade to come, this publication (festschrift) will begin with a history of the organization – a good story that really hasn’t been told. This brief history will be followed by

first-person accounts (quotes) by individuals connected to the organization's work together with several "memorable moment" pages."

Over time, the EATG has adapted as a patient-led NGO. It has gone from addressing an emergency situation across Europe – one that unfortunately still exists in some parts of the WHO European Region – to focusing on the long-term well-being of people living with HIV. To this day, self-stigma persists. It is often fomented by structural stigma and the criminalisation of risk behaviours and compounded by ageism. Health-related quality of life is also lower among those living with HIV, and governments and international agencies continue doing very little about it. That's why it is no surprise that alongside Dr Jane Anderson, Nikos and I created the HIV Outcomes Beyond Viral Suppression Initiative in 2016. This undertaking meant a chance for us to focus on the so-called "right" side of the continuum of care and we are thrilled to see HRQoL included in the new WHO strategy.

Looking ahead to the horizon, the EATG has shown that it will continue steadfast in its mission. Not only is it leading the way in HIV and many co-infections, but it has already stepped up to confront the most recent challenge of multimorbidity.

2007
UNITED KINGDOM

The 2000s

54

EATG AND THE POWER OF ECAB

30
YEARS

Paul Clift



EATG member

I joined EATG many years ago, through the old route of first joining ECAB (European Community Advisory Board). It was not an easy process, but it was well worth it. Since then, my ongoing involvement with EATG has been mainly as a member of ECAB and, following the restructure, as a member of Partners in Science. I have learned much from my involvement in EATG, not least how to engage with powerful pharmaceutical companies at the transnational level, how to apply what I learn in ECAB meetings to the situation in my country (England, but with a strong focus on my home city of London), how to engage and work with fellow activists from other countries (not least with regard to rules of discourse and ways of making sense of society, which differ from country to country).

However personally rewarding they later became, my first ECAB meetings were challenging! Firstly, because at that time new members were asked to give a 10-minute presentation of who they are, and to describe the work they do in their own country. Secondly because it became very clear, very quickly, that everyone in the room was a highly knowledgeable expert in treatments, in anti-retrovirals and how they work on the HIV replication cycle; experts too, on each pharmaceutical company and the drugs that each company had in the development pipeline. As a new member, I was put on a very steep learning curve.

The key achievement of EATG is right in front of us all the time, it's one that we too easily forget: that a community-based organisation was created by community for community across all of Europe and that, despite huge challenges, it still exists and it still functions. This is a tribute to the founders back in 1992, and to the members now.

By this time, around fifteen years ago, ECAB was well established as a patient advisory group – established by community, for community. This is one of EATG/ECAB's big achievements and ongoing strengths, that patient advisory groups were – and sometimes still are – set up by pharmaceutical companies, according to criteria set by the companies. Here, we have activists setting up a group by and for ourselves, so that interactions with industry are on our terms rather than theirs. Working through this group we 'provide meaningful, independent, and valued input in research on treatment, prevention and quality of life for HIV and its main co-infections.' I think the companies do value our input in these meetings, even though they do not always do exactly what we ask. Nevertheless, we continue making our arguments for effective PrEP and for improved ART direct to the pharmaceutical companies in meetings that take place in confidentiality so we can speak always openly and as strongly as necessary. This activity is central to EATG, and it is not to be taken for granted.

Going right back to beginnings in 1992 when a group of activists and advocates got together and formed the group that evolved into the EATG that we know today, was a very different time for the treatment of HIV. Politically, it was a world away from where we are now. The UK was a member of the EU, with all that implies for the exchange (actually, the flow) of ideas and innovation and activism; and it was a time of world-historical change in Eastern and Central Europe. Our region continues to go through change and trauma of various kinds, but somehow EATG 'holds steady' for the benefit of our members, enabling us to support and encourage each other across borders.

This means that the key achievement of EATG is right in front of us all the time, it's one that we too easily forget: that a community-based organisation was created by community for community across all of Europe and that, despite huge challenges, it still exists and it still functions. This is a tribute to the founders back in 1992, and to the members now.

2007

DENMARK

The 2000s

58

**EATG'S
CONTRIBUTION
TO EUROPEAN-WIDE
HIV TESTING
INITIATIVES**

30
YEARS

Dorthe Raben



EuroTEST
CHIP

EuroTEST, originally named HIV in Europe, was initiated in 2007 at a conference in Brussels to bring attention to the importance of ensuring people living with HIV are diagnosed earlier and receive optimal care promptly. The idea driving the initiative was the need for different stakeholders to work together and overcome continuing issues around late diagnosis and the large proportion of undiagnosed people with HIV across Europe. EATG, as a European patient-led organization, was an important partner from the beginning, giving voice to affected communities.

Since its launch, HIV in Europe has built a European platform where independent experts from civil society, policy institutions, health care, and European public health institutions work together towards influencing policy, knowledge sharing, and building the evidence-base to support earlier diagnosis and care of people living with HIV and viral hepatitis across Europe.

There is still a need for a strong pan-European community-led organisation that can give voice to affected communities and advocate for continued focus on tackling HIV and related diseases at European and national levels.

In 2009, the initiative was complemented by a coordinating secretariat at the Centre of Excellence for Health, Immunity, and Infections (CHIP) at Rigshospitalet, Copenhagen, led by Professor of Infectious Diseases, Jens Lundgren, an Advocacy Secretariat at EATG in Brussels and a Financial Secretariat with AidsFonds Netherlands.

Since then, EATG has continued to work towards putting early testing, diagnosis, and care high on the EU political agenda, reporting to the EuroTEST Steering Committee on developments at an EU level. EATG made a significant contribution to the biennial conferences HepHIV, and European Testing Week.

There is still a need for a strong pan-European community-led organisation that can give voice to affected communities and advocate for continued focus on tackling HIV and related diseases at European and national levels. This includes involvement of communities in planning and implementing clinical research.





THE 2010s

BRYAN
2011 | FRANCE

EDWIN
2012 | NETHERLANDS

HARRIET
2014 | GERMANY

MORGAN
2015 | UK

DIVERSE VOICES FOR HEALTHY LIVING
BRYAN TEIXEIRA

HOW EATG HELPED BUILD A EUROPEAN –
AND ULTIMATELY GLOBAL – MOVEMENT
TO END HIV CRIMINALISATION
EDWIN J BERNARD

PROGRESS IS A SNAIL:
GROWING FROM GAY AIDS
ACTIVISM TO DEFENDING
HUMAN RIGHTS OF PEOPLE
IN THE HIV CONTEXT
HARRIET LANGANKE



DENIS
2016 | UK

MAGDALENA
2017 | POLAND

JACKIE
2017 | UK

ANDRIY
2022 | UKRAINE

COLLABORATION WITH EATG IN EMERGE,
AND THE DEVELOPMENT OF DIGITAL PLATFORMS
MORGAN FRASER

EATG: VALUING PEOPLE AND PARTNERSHIPS
DENIS ONYANGO

EATG AND HIV ACTIVISM IN POLAND
MAGDALENA ANKIERSZTEJN-BARTCZAK

EATG AS A FLEXIBLE
AND AGILE EUROPEAN ORGANISATION
ANDRIY KLEPIKOV

2011

FRANCE

The 2010s

66

DIVERSE VOICES FOR HEALTHY LIVING

30
YEARS

Bryan Teixeira



EATG member

Since its inception in 1991, EATG members have focused on the goal of amplifying the voices of people living with and affected by HIV within national and regional policy and decision-making processes. This goal has driven many of the internal and external changes in EATG's activities over the years.

EATG began with an expansive vision to change the way HIV research was done in Europe to ensure community access and pan-European dialogue on treatment issues. While the early members were exclusively Western European, the group grew quickly to include Central Europeans from Hungary and Turkey. Participation in EATG's membership and events then quickly expanded to include people living with and affected by HIV from other states in Central and Eastern Europe and Central Asia, e.g., Belarus, Bulgaria, Estonia, Georgia, Latvia, Lithuania, Macedonia, Moldova, Poland, the Russian Federation, and Ukraine. The official expansion of EATG's geographic remit to include the entire WHO European region of 53 nations, across Europe and into Central Asia, contributed significantly to this momentum. Including voices from across Europe and Central Asia continues to be central to EATG's work, and its current Long-Term Strategy 2020-2025 highly values this diversity of voices.

However, EATG has not only worked to amplify voices from across Europe and Central Asia, it has also worked to diversify its reach and engage with a broader constituency of people living with or affected by HIV,

EATG has worked to diversify its reach and engage with a broader constituency of people living with or affected by HIV, including migrants and other people on the move, women, people living with co-infections like TB and viral hepatitis, youth (under 25) and older (over 50), people with mental health challenges, and sex workers.

including migrants and other people on the move, women, people living with co-infections like TB and viral hepatitis, youth (under 25) and older (over 50), people with mental health challenges, and sex workers. In 2015, EATG initiated a series of three conferences on Ageing and HIV to put this topic firmly on European policy agendas. More recently, EATG has become a leader in discussions about mental health research and policy in the lives of people living with and affected by HIV, e.g., addressing cognitive impairment, loneliness, depression, and drug-drug interactions. In 2022, EATG completed a collaboration with the e-MPOWER project on training youth sex worker activists. And, currently, EATG members continue to actively support Ukrainians living with and affected by HIV who are refugees because of the war with Russia.

So, what next for EATG in its ongoing role of amplifying the voices of people living with and affected by HIV within key policy and decision-making processes? Is anyone being left behind?

Clearly, more still needs to be done relative to the various voices with which EATG has so far been engaged, especially as we look to ending AIDS by 2030. Amplifying voices against stigma and discrimination, against barriers to services, and for improved engagement in research and policy will no doubt continue, as will the need for more voices calling for fair pricing of medications and sustainable services. EATG could begin to engage more effectively with representatives of people with disabilities, prisoners, and other people in detention. There is also the dark global cloud of climate breakdown that overshadows everything. It will no doubt be especially important to hear from people ageing with HIV who are more vulnerable to increased morbidity and mortality due to heatwaves.

EATG has a lot to do in the next eight years as we look to our global 2030 targets!

2012

The 2010s

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THE NETHERLANDS

HOW EATG HELPED BUILD A EUROPEAN – AND ULTIMATELY GLOBAL – MOVEMENT TO END HIV CRIMINALISATION

30
YEARS

Edwin J Bernard



HIV Justice Network

It was ten years ago – on the eve of EATG’s 20th Anniversary General Assembly in Berlin – that my dream of a pan-European movement to end HIV criminalisation came together. After years of yearning for a more co-ordinated approach to ending the inappropriate use of the criminal law to control and punish people living with HIV based on our HIV-positive status (HIV criminalisation), it was clear to me that, in order to make a real difference, advocates and experts in law, science, policy and human rights needed to meet in person to connect and strategize about this often underfunded and overlooked issue.

So, early in 2012, I was honoured and excited to be asked by EATG to lead the organisation of what would be a memorable and intense full day meeting along with local co-hosts Deutsche AIDS-Hilfe and with support from the International Planned Parenthood Federation (IPPF) and the HIV in Europe initiative.

Early in 2012, I was honoured and excited to be asked by EATG to lead the organisation of what would be a memorable and intense full day meeting along with local co-hosts Deutsche AIDS-Hilfe and with support from the International Planned Parenthood Federation (IPPF) and the HIV in Europe initiative. The timing was crucial for Europe, which was at the time seeing the highest number of HIV criminalisation cases in the world, after North America.

The event ended up bringing together a wide range of civil society advocates from across Europe and central Asia, along with representatives of UNAIDS and UNDP and other human rights experts, scientists, and clinicians – and even a prosecutor (Arwel Jones from the Crown Prosecution Service of England and Wales) and a parliamentarian (Austrian MP, Petra Bayr), too!

I had organised a number of smaller meetings prior this, including a civil society meeting in February of that year that led to the creation of the Oslo Declaration on HIV Criminalisation.¹ However, I had never pulled together a full day meeting of this size and scope before. It was a steep learning curve that stood me in good stead for my future role as global co-ordinator of the HIV JUSTICE WORLDWIDE coalition,² launched in 2016.

The timing was crucial for Europe, which was at the time seeing the highest number of HIV criminalisation cases in the world, after North America. Many people were being prosecuted and punished for perceived 'HIV exposure' despite there being no risk of HIV transmission. Years before the U = U movement, we were already alive to the fact that effective HIV treatment was at least as reliable an HIV prevention tool as condoms, yet this scientific advance was only beginning to be recognised in law and policy. So, we especially wanted to ensure a better understanding of the latest scientific and medical evidence, along with legal principles and human rights concepts.

1 Available here: <https://www.hivjustice.net/news/international-civil-society-experts-launch-the-oslo-declaration-on-hiv-criminalisation/>

2 Available here: <https://hivjusticeworldwide.org>

It was here that lessons learned from Denmark (which had suspended its HIV law in 2022)³ and Switzerland (which recognised the prevention benefit of treatment following the 2008 'Swiss Statement')⁴ were discussed and disseminated. A key outcome of those discussions led to the creation of the 2018 'Expert Consensus Statement on the Science of HIV in the Context of Criminal Law'⁵ which has since made a significant difference⁶ to the way people with HIV are treated in criminal cases, discussed in parliament, and in media reporting, globally.

This was also one of the first times that the newly created HIV Justice Network⁷ – of which I am now the executive director – had a platform, and we premiered our first advocacy video documentary, *Doing HIV Justice*,⁸ about the creation of prosecutorial guidance in England & Wales. In a workshop following the screening, lessons learned from both England & Wales, and from Scotland, about how such guidance could limit the overly broad use of the criminal law – and help educate

3 More information here: <https://www.hivjustice.net/country/dk/>

4 More information here: <https://www.aidsmap.com/news/jan-2008/swiss-experts-say-individuals-undetectable-viral-load-and-no-sti-cannot-transmit-hiv>

5 More information here: <https://www.hivjusticeworldwide.org/en/expert-statement/>

6 As found here: <https://www.hivjustice.net/publication/use-of-the-expert-consensus-statement-on-the-science-of-hiv-in-the-context-of-criminal-law/>

7 <https://www.hivjustice.net/>

8 Available here: <https://www.hivjustice.net/video/doing-hiv-justice/>

the entire criminal legal system about HIV – were discussed. And it was here that the seed was planted for the eventual publication of UNDP’s globally relevant Guidance for prosecutors on HIV-related criminal cases in 2021.⁹

So much of what we discussed that day is still relevant for the HIV movement. And fortunately, we have a video record of the day which you can find online.¹⁰

In fact, the workshop on how to advocate for prosecutorial guidance remains as useful today as it was a decade ago, and you can find that – along with our ‘Doing HIV Justice’ documentary and Arwel Jones’s inspired introduction, in a YouTube playlist.¹¹

9 Available here: <https://www.hivjustice.net/news/a-crucial-new-advocacy-tool-to-challenge-hiv-criminalisation/>

10 Available here: <https://vimeo.com/showcase/2122809>

11 Available here: https://www.youtube.com/playlist?list=PLxjlWso6S3mGW7pY2U_2aYHxrzBJsoRFA

2014

GERMANY

The 2010s

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**PROGRESS
IS A SNAIL:
GROWING FROM
GAY AIDS ACTIVISM
TO DEFENDING HUMAN
RIGHTS OF PEOPLE
IN THE HIV CONTEXT**

30
YEARS

Harriet Langanke



EATG member

GSSG – Germany's
Charitable Foundation
Sexuality and Health

In the same year the European AIDS Treatment Group (EATG) was founded in 1992, I co-founded the national Network Women and AIDS in Germany. I remember very well those days when we said AIDS – and meant just that. Not HIV. Living with HIV could not be seen as a having chronic condition, it was much more of a sentence. There was no treatment, no medication, not much hope and a lot of fear, primarily among men. Especially among gay men. Until today, HIV in Germany is much more common among men who have sex with men (MSM). Thirty years ago, this meant, that MSM had to fight to survive. There was so much discrimination against MSM, so much stigma that there was little space for solidarity and cohesion with the few women who shared the same diagnosis, AIDS.

EATG was founded by a handful of brave, smart, dedicated, and skilled men. Most of them MSM, all of them committed to what the organisation was called to do: Ensure treatment for AIDS, the disease that brought me and many others to more sick bays and funerals than one would expect for people of our age. Yes, we were young, those thirty years ago. We all felt helpless, angry, and willing to challenge politicians, researchers, pharma companies, and doctors.

In the early 1990s, the world appeared even more patriarchal than today. And so was EATG. The organisation was dominated by men, and no one was even questioning this fact. Why should we? AIDS was a threat for MSM much more than for women, we were sure. However, I do remember how difficult it

EATG has become an organisation that welcomes female members. Within the ten years of my membership, EATG has established structures and routines that ensure women's visibility, equality, and fairness.

was for women to join EATG. My female friends in the national Women's Network shared their stories about feeling bullied. Their expertise was questioned, their contributions belittled.

In those early years, the tone was rough in EATG. For men and for women – and for all the genders that we did not name thirty years ago. There was little time for friendliness, for soothing solidarity or empowering empathy. Still, gay men had something more in common than AIDS treatment. Being gay and being discriminated for their sexual orientation made them unite. They were so united that it was hard for the few women who also were dedicated to improving AIDS treatment.

In those days, it never seemed interesting, not to say rewarding to me to become a member of this men's club. I watched them closely from my comfortable position in Germany's AIDS foundation and in the Women's Network. I've seen the commitment, the personal dedication, the outstanding quality of their activism. But I never even thought of joining EATG. It just did not feel welcoming for women, whether they lived with AIDS or HIV, or not, or whether they were qualified by education or training. Too often I had to listen to the stories from inside EATG that were nothing but misogynist.

German Noble Prize winner for literature, Günter Grass, once wrote, "Progress is a snail." He was right, and I watched EATG from the outside for almost twenty years. But, ten years ago, I was invited to join. I admit, I was sort of scared. Would I find the hostile environment my female network friends had described? Would women's issues be put into separate sections? Isolated from the - gay - men's world? Would I need my national women's network to back me up?

Fortunately, that's not the case. Women are of course now represented in the bodies of the organisation. EATG has become an organisation that welcomes female members. Within the ten years of my membership, EATG has established structures and routines that ensure women's visibility, equality, and fairness. Women are encouraged and empowered, just like any member. EATG has become a safe space for women.

Sounds good? Yes. But as a sexologist, a sexual health expert and a feminist, I won't allow EATG to stay binary. AIDS activism has always been an HIV and human rights movement. Therefore, I want to quote another German speaking author, Marie von Ebner-Eschenbach. This 19th century poet wrote, "What we do today determines what the world will look like tomorrow." Thus, I not only congratulate EATG on its enormous progress during the last 30 years. I also demand that we as EATG stay determined to treat HIV, protect sexual health and rights, and grow as a united group of people to make AIDS history.

2015

The 2010s

80

UNITED KINGDOM

COLLABORATION WITH EATG IN EMERGE, AND THE DEVELOPMENT OF DIGITAL PLATFORMS

30
YEARS

Morgan Fraser



EmERGE mHealth Ltd

At EmERGE mHealth Ltd, we have a great relationship with EATG, having worked closely with them since 2015. Originally, we worked in partnership with EATG on the EU-funded EmERGE project, in which the project teams co-designed, developed, implemented, and evaluated a digital health pathway and platform for people living with HIV.

EmERGE mHealth is the not-for-profit company that was formed from the project to ensure that the digital platform continued to be available to clinics and communities beyond the end of the project in a sustainable way.

It was clear to us throughout the project that EATG has an amazing dedication to HIV advocacy across Europe. They played a substantial role in the project, doing an incredible job as the lead partner for the dissemination and popularisation of the project, and in co-leading on co-design - ensuring that co-design was embedded throughout the project in a meaningful way via their network of community partners across Europe. They established a brilliant (and effective) website for the project that contained vital information for both end-users and members of the public. Furthermore, EATG were regular enablers of good practice and offered opportunities for people to get involved in discussions around the project. They have been very committed to the dissemination of project outcomes, regularly engaging the HIV community as well as the HIV and mHealth scientific communities. The project benefitted massively by having EATG as a project

It was clear to us throughout the project that EATG has an amazing dedication to HIV advocacy across Europe.

partner, specifically because they were determined to go beyond what was expected of them in the aim of serving the HIV community. They informed policy at national, European, and international levels, advocating for the benefits of mHealth in HIV and potentially other areas too.

Beyond this project, after it finished in 2020, it was clear to us that our relationship with EATG was vital to the success of the EmERGE platform. Therefore, we've continued to work with EATG as a formal partner to the not-for-profit company - discussing key dissemination and advocacy issues with them. Beyond the EmERGE project and into our development of the EmERGE mHealth, our formal partnership with EATG continues to ensure that the company and product value propositions are aligned to our app user base. EATG can support a collaborative approach to new deployments founded on community support at new sites. We are also working with EATG as a trusted partner to develop the EmERGE mHealth website. Working with EATG on this was a no-brainer as the success of the EmERGE project website proved vital to the dissemination of key information, including links to conference papers and regular updates.

It is very much our opinion that our partnership with EATG has been imperative to both the success of the completed project and the newly established not for profit company. We look forward to continuing to work with EATG in the future as they have proven themselves to be a vital partner in our work with people living with HIV and continue to be the face of HIV advocacy across the European region.

2016

UNITED KINGDOM

The 2010s

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EATG: VALUING PEOPLE AND PARTNERSHIPS

30
YEARS

Denis Onyango



EATG member
Africa Advocacy
Foundation

I joined EATG in 2016, about a couple of years after I became aware of its work in representing the interests of people living with HIV and improving access to prevention, HIV testing and treatment, hepatitis, TB, and other conditions.

My late friend, Elias Phiri, played a key role in my decision to join EATG. I was also inspired by the crucial role the organisation played – and still plays – in influencing policy, advancing learning, scientific research, and training for the benefit of the patient community in Europe and beyond.

One of the memorable experiences for me as a new member was attending an ECAB meeting in Brussels in 2016. I saw the incredible expertise members had in HIV science. I remember being in awe of just how knowledgeable individuals like Maxime, Nikos, Luis, and Stefan were. Their ability to articulate ideas and interrogate scientific data presented by the industry inspired me to learn more about HIV and improve myself as a member.

There has always been a willingness to involve everyone, even those who may not be highly knowledgeable. The humility of EATG staff like Koen Block, Giorgio Barbareschi, and ECAB chair Giulio Corbelli was very reassuring.

I strongly believe that EATG is a genuinely caring organisation that provides a unique platform for individuals to grow and have a meaningful say on issues that affect us, such as quality of life, asserting the rights of marginalised, or challenging unjust laws. It truly values people and partnerships.

I also had the opportunity to work with EATG as a partner, delivering the M-Care training programme from around 2017. As a migrant in Europe, I understand and have experienced first-hand the challenges and barriers to accessing opportunities, engaging with services, and influencing policy. The partnership with EATG genuinely contributed to many migrants across Europe being empowered to become effective advocates for their respective communities. The current Mi-Health initiative (the phrase 'Mi-Health' was coined by Koen, the former EATG Chief Executive) owes a lot of its capacity building and community of practice to the support EATG and its members provided. It is a legacy for which we as a migrant community are proud.

My engagement with EATG so far has also been inspiring and helpful on a personal level. The organisation provided me with the learning, insights, and skills to become an effective community advocate. I have gained skills necessary to engage with key stakeholders, network, mobilise resources and manage projects.

I strongly believe that EATG is a genuinely caring organisation that provides a unique platform for individuals to grow and have a meaningful say on issues that affect us, such as quality of life, asserting the rights of marginalised, or challenging unjust laws. It truly values people and partnerships.

2017

POLAND

The 2010s

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EATG AND HIV ACTIVISM IN POLAND

30
YEARS

Magdalena Ankiersztejn-Bartczak



EATG member
Foundation
for Social Education

I have known about EATG since the beginning of my work in HIV. When I started my HIV story 20 years ago, I met Wojciech Tomczyński, the most famous and committed HIV activist in Poland and one of the few people talking openly about his infection. He introduced me to international activities and was already a member of EATG.

Working for people living with HIV has been and continues to be my priority. Both professionally and privately, I surround myself with seropositive people. My project and academic work at the Social Education Foundation focuses on HIV. I have admired EATG for years and knew many of members from various meetings, workshops, or conferences.

I love the strong energy and positive outlook of EATG members. Often, when I am fed up with difficult situations in my country, I get amazing support from EATG. This gives me the energy and the will to move forward.

My application to be a member of the EATG was a long time in the making. EATG was undergoing organisational change at the time but, happily, on 27th November 2017, I was accepted and the next phase of my cooperation with the EATG began.

The COVID-19 pandemic has been my time of greatest involvement in EATG's activities. I couldn't travel due to restrictions, and it so happened I saw EATG members online more often than my colleagues in other Polish organisations. I love the strong energy and positive outlook of EATG members. Often, when I am fed up with difficult situations in my country, I get amazing support from EATG. This gives me the energy and the will to move forward.

It is also fantastic to be a member of three working groups: Combination Prevention, Partners in Science, and Quality of Life. In each, there is a super team and the opportunity to exchange knowledge and experience.

2017

The 2010s

92

UNITED KINGDOM

EATG'S GOVERNANCE: RESPONSIBILITY, ACCOUNTABILITY, AND ENSURING A STRONG BOARD OF DIRECTORS

30
YEARS

Jackie Morton



Former EATG member
Retired NHS Manager

Being appointed to EATG's Board at the General Assembly in 2017 threw together five different but eminent and passionate members of the organisation. We had a broad range of abilities, knowledge, and skills, and as we sat together for the first time at a lunch meeting post-selection, we took the traditional approach to allocating key positions on the board. Selection of the chair, the treasurer, the board secretary, and board members of existing arms of training and development, bringing together the guardians of this well-established organisation.

Trying to ensure the organisation achieved the outcomes of its newly agreed strategy, our first year together as a board was quite turbulent as we adjusted to our roles. At its year end in 2018, we reflected on our performance, and realised that we needed to better understand our role and function as board members. At this time, I was also asked to be chair of the board, which felt a daunting task leading this large European organisation. What was our goal and was the board fit for purpose? If we were there to ensure the organisation achieved its goals and maintained its legal and ethical integrity with minimum risk, then we as a board – the organisation's 'champions' – needed to be capable of overseeing EATG's functioning.

To this end, we embarked on an exploration of the Carver Model of Policy Governance. This approach explores the ownership of an organisation, though in the context of EATG this is not straightforward. Who are

As for the result of the review, at the end of our terms as board members, it was pleasing to see that we were beginning to work together as a competent and effective board. We were confident about handing the baton on to the next board members.

the owners? Its members, its founders, people living with HIV, or donors providing funds towards specific outputs?

The process of reviewing EATG's governance involved a range of members in what became a complicated process which did, in the end, bring some clarity on the board's purpose. This included being able to hold the Executive Director to account and defining how EATG could achieve its products and services within its financial resources. The review also defined the board's purpose, and that being able to govern the organisation utilising a framework that had existed since its inauguration in 1992 required a strong board model. Its owners, the members, need the board to retain its 'guardian' function to ensure the Executive Director (selected by the Board) delivers on EATG's strategy, demonstrating effective planning of its products and services. The board's roles were clearly to oversee EATG's governance and the financial health of the organisation, ensure effective planning and a leadership structure that would meet the required standards of legal and ethical integrity, and enhance the organisation's public standing.

Our role as a board means steering the organisation towards a successful future by attending meetings as required when available, standing on or attending ad hoc committees, being prepared for the meetings, and by reading the agenda and supporting materials prior to board meetings. We sought to engage on the issues at hand. We explored the mission and policies of the organisation with the purpose of promoting its mission and at the same time seeking to maintain a proper distance, so the ED is the manager of the organisation.

As for the result of the review, at the end of our terms as board members, it was pleasing to see that we were beginning to work together as a competent and effective board. We were confident about handing the baton on to the next board members, and hopefully, some of what we learned will help future board members in their role.

It is with grateful thanks to all that took an active part in the review of the governance model. In remembrance of Caroline Oliver, Carver Policy Governance lead, who guided the board through this analysis of governance at a time when she too needed support. Unfortunately, Caroline passed away just weeks after completing her consultancy with EATG having insisted on completing her consultancy report when on her death bed. An amazing woman. R.I.P.

2022

UKRAINE

EATG AS A FLEXIBLE AND AGILE EUROPEAN ORGANISATION

30
YEARS

Andriy Klepikov



Alliance for Public Health

First, congratulations for EATG's 30th anniversary. With great appreciation to EATG's work, I'm sending my comments below. Reflecting on the role EATG has played over the past 30 years in HIV advocacy across the European region, EATG's involvement in HIV advocacy has led to it being recognised across Europe. Hundreds of thousands, or even millions of Europeans are benefiting from this successful advocacy, focusing not only on access to treatment but also on access to up-to-date science-based innovations. EATG is the organisation which has a unique combination of skills and principles – being community driven, science based, being program, policy, and community focused, successfully combining prioritisation of both Western and Eastern Europe. These are key priorities for going forward!

One of the advantages of EATG is around its organisational flexibility and agility. When Russia started the war and invaded Ukraine, EATG was among the first to offer a helping hand, solidarity, and support.

EATG does face challenges in the future. Access to treatment is still not sufficient. Access to innovations is still extremely limited. People living with HIV and key populations are still stigmatised and marginalised in several countries. At the same time, we see with limited resources, space for communities and civil society is shrinking. There is a lot to do. And communities and civil society should be key partners for going forward. It is important to intensify EATG's work, attracting resources and expertise for addressing challenges and barriers in the HIV response.

As to achievements, EATG prioritises real things which matter. These include access to quality treatment, quality of life of HIV+ people and key populations, being flexible and prioritising person-centred approaches, diversity, and special needs: for example, being an HIV+ adolescent and aging with HIV are both important.

In Eastern Europe and Central Asia, EATG prioritised sharing best practice, mutual exchange and learning between Western and Eastern Europe. Learning mechanisms such as the Step-Up Academy has proven its great impact in improving programs, boosting advocacy, and changing policies.

One of the advantages of EATG is around its organisational flexibility and agility. When Russia started the war and invaded Ukraine, EATG was among the first to offer a helping hand, solidarity, and support.





IN MEMORIAM

We have lost many members, friends and allies since 1992, whose passion and commitment have empowered and inspired us. Many of them were instrumental in the establishment and development of the EATG, and will always remain part of our extended family. It is to their memory that we dedicate EATG's continuing work.

Andreas **Salmen** (d: 1992)

Marc **Regnard** (d: 1992)

Michael **Fischer** (d: 1992)

Jan B. **Haan** (d: 1993)

Cord **Ebeling** (d: 1993)

Olov **Wendelborg** (1963–1994)

Nathalie **Dagron** (1960–1995)

Marina **Bichetti** (d: 1997)

Jørgen **Haahr Kristensen** (d: 1997)

Jürgen **Poppinger** (d: 1997)

Julio **Silveira** (d: 1997)

Jeannine **van Woerkom** (1954–1997)

Svetlana **Denk** (d: 2001)

Pedro Jorge Eduardo
da Silva Santos (1962–2002)

Maurizio **Pancanti** (d: 2003)

Arjen **Broekhuizen** (1955–2004)

Eric J. **Welling** (1956–2004)

Albert Rúnar **Aðalsteinsson** (1950–2006)

François **Wasserfallen** (1962–2008)

Gideon **Hirsch** (1960–2008)

Roy **Arad** (1978–2010)

Jerzy Jurek **Domaradzki** (1949–2011)

Kees **Rümke** (1958–2014)

Bob **Munk** (1953–2015)

Paul **Blanchard** (1964–2016)

Zak **Kostopoulos** (1985–2018)

David **Ananiashvili** (d: 2018)

Dénes **Bánhegyi** (1944–2019)

Elias **Phiri** (1967–2021)

Giulio Maria **Corbelli** (1966–2022)

30 years EATG: Reflect, Recover, Regroup

This year the **European AIDS Treatment Group (EATG)** turns thirty.

It has been a journey through peaks and valleys, a battle with wins and defeats. All these years' losses and triumphs have only kept us growing stronger with our treatment activism.

We have worked for and witnessed life-changing medical achievements that gave us back our lives.

We have lost friends, partners, family members and allies that left too early to benefit from these achievements. We mourn for those we are still losing, being too late to access them.

We have realised that long after the tools have been available, our communities still have to fight to access them for a series of reasons.

We are still here for them and for us.

For our thirty years we take the opportunity to **reflect** on our wins and losses as well as on our future challenges, **recover** from what brought us down and **regroup** with our members, communities and allies.

The journey continues

[#ReflectRecoverRegroup](#)

[#EATG30](#)

About the European AIDS Treatment Group

The European AIDS Treatment Group (EATG) is a patient-led NGO that advocates for the rights and interests of people living with or affected by HIV/ AIDS and related co-infections within the WHO Europe region. Founded in 1992, the EATG is a network of more than 150 members from 45 countries in Europe. Our members are PLHIV and representatives of different communities affected by HIV/AIDS and co-infections. EATG represents the diversity of more than 2.3 million people living with HIV in Europe as well as those affected by HIV/AIDS and co-infections.

For more information, please visit www.eatg.org

www.eatg.org

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