



Transparency Register

Profile of registrant

European AIDS Treatment Group

Identification number in the register: **49959188061-85**

Registration date: **13/02/2012 16:32:26**

The registrant performed the last (partial or annual) update on: **27/04/2021 11:24:04**

The date of the last annual update was: **27/04/2021 11:24:04**

Next annual update due latest on: **27/04/2022**

Registrant : Organisation or self-employed individual

(Organisation) name:

European AIDS Treatment Group

Acronym:

EATG

Legal status:

NGO

Website:

<http://www.eatg.org>

Section of registration

Section:

III - Non-governmental organisations

and more precisely:

Non-governmental organisations, platforms and networks and similar

Contact details

Contact details of organisation's head office:

Mettmanner Strasse, 24-26

Duesseldorf 40233

GERMANY

Telephone number:

(+32)26269640

Contact details of the organisation's Belgium office:

Interoffices Avenue des Arts 56-4c
Brussels 1000
BELGIUM

Telephone number:

(+32)26269640

Person with legal responsibility**Name, Surname:**

Mr Ricardo Fernandes

Position:

Chair

Person in charge of EU relations**Name, Surname:**

Mr Pieter Vanholder

Position:

Executive Director

Goals / remit**Goals / remit of the organisation:**

For 2020-2025, EATG's mission is:

Equitable, speedy and sustainable access to:

- effective treatments and holistic care for all people living with HIV and associated infections and morbidities, and
- effective prevention and diagnosis for all communities affected by HIV and associated infections and morbidities.

EATG will focus on 3 Programme Areas:

Quality of Life In line with its mission to advance equitable, speedy and sustainable access to effective treatments and holistic care for all people living with HIV and associated infections and morbidities.

Combination Prevention

In line with its mission to advance equitable, speedy and sustainable access to effective prevention and diagnosis for all.

Partners in Science

In line with its mission to advance equitable, speedy and sustainable access to effective treatments and holistic care for all people living with HIV and associated infections and morbidities.

The organisation is active on the following level(s):

European

Specific activities covered by the Register

Main EU legislative proposals or policies targeted:

- EU Pharmaceutical Strategy - Timely patient access to affordable medicines : consultation on the roadmap
- Proposal for a REGULATION OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL on the establishment of a Programme for the Union's action in the field of health -for the period 2021-2027 and repealing Regulation (EU) No 282/2014 ("EU4Health Programme")
- COM/2020/405 final and European Parliament EU4Health draft report
- Communication COM/2018/233 final on enabling the digital transformation of health and care in the Digital Single Market; empowering citizens and building a healthier society
- Cancer mission recommendation
- EU drug policy post-2020

Previous input/submissions:

- COMMISSION STAFF WORKING DOCUMENT SWD(2018) 387 final on Combatting HIV/AIDS, viral hepatitis and tuberculosis in the European Union and neighbouring countries - State of play, policy instruments and good practices
- Submission to EMA Consultation on the Role of big data for evaluation and supervision of medicines in the EU
- submission to EU drugs strategy 2013-20 – evaluation consultation(December 2019-Feb 2020);
- submission to EU Drugs Agenda and Action Plan consultation in June-July 2020
- ECDC: Public health guidance on HIV, hepatitis B and C testing in the EU/EEA: input as expert, 2018

Relevant policy implementation, public relations and communication activities such as projects, events and publications:

EU Civil Society forum on HIV, TB and Hepatitis coordination with AAE, EHRA, Correlations, TBEC. EATG act as secretariat together with AAE.

HIVACAR – EVALUATING A COMBINATION OF IMMUNE-BASED THERAPIES TO ACHIEVE A FUNCTIONAL CURE OF HIV INFECTION. The project aims to change the current paradigm of HIV treatment by obtaining a functional cure for HIV thanks to effectively targeting residual virus replication and viral reservoirs.

EHVA – EUROPEAN HIV VACCINE ALLIANCE, AN EU PLATFORM FOR THE DISCOVERY AND EVALUATION OF NOVEL PROPHYLACTIC AND THERAPEUTIC VACCINE CANDIDATES. Project aims: To develop a Multidisciplinary Vaccine Platform (MVP) in the fields of prophylactic and therapeutic HIV vaccines. The MVP includes four components: 1) Discovery, 2) Immune Profiling, 3) Data Management, Integration and Down-Selection, and 4) Clinical Trials.

PROMs in HIV Research and Development: Analysis of Community Needs and Engagement - In March 2021 EATG launched the report on the use of Patient Reported Outcome Measures (PROMs) for the development of new HIV medicines. Led by the community, the work comprised of a literature review, a survey with people living with HIV taking treatment and stakeholder interviews. The purpose of the work is to describe the current use of PROMs in HIV research and development as well as to inform an advocacy agenda to guide the use and development of PROMs, highlighting the role of communities living with or affected by HIV. It provides a concrete set of recommendations for people living with HIV, pharmaceutical companies, researchers/clinicians and regulatory bodies/HTAs.

<https://bit.ly/eatg-promise-leaflet> <https://bit.ly/eatg-promise-booklet> <https://bit.ly/eatg-promise-referencepaper>

From Mar 2020 to Jan 2021, EATG documented the impact of the disruption caused by the SARS-COV2 pandemic on people living with or most affected by HIV and solutions found to mitigate it, including at community level. EATG published 6 bulletins, organised mutual learning e-meetings on HIV self-testing, ensuring continuity in sexual health services, COVID-19 vaccines, adaptation of services at community level. It presented findings at scientific conferences and a WHO-ECDC meeting on national HIV and Hepatitis coordinators. It was also part of the working group of EuroTEST (eurotest.org) to assess the impact of the crisis on HIV, TB, viral hepatitis and STIs testing survey.

<https://linktr.ee/eatgcovid19>

From Mar 2020 to Apr 2021, EATG conducted a desk research on the interplay of mental health, well-being and HIV. The desk research included a literature review as well as a European-wide survey on the community perspective on the role of mental health in HIV prevention, treatment adherence, quality of life and retention in care. The reports will be launched at a multistakeholder meeting starting in April 2021. A workshop focusing on key thematic areas that were identified in the research was organised in Jan 2021, to elaborate specific recommendations on practical interventions in community and healthcare settings that can effectively address the key elements of the interplay of mental health and HIV. A briefing paper capturing the elaborated recommendations will also be discussed during the first part of the multistakeholder meeting.

In 2020, as part of the EmERGE project (<https://www.emergeproject.eu>), EATG worked on two publications: 1) "Policy and practice guidelines: Report on guidelines to support co-design for improved usability, acceptability and patient outcomes in mHealth developments" and 2) "How EmERGE addressed barriers to the implementation of mHealth", which looked at barriers that exist when implementing mHealth solutions and how the EmERGE project was able to anticipate many of these and, where unexpected challenges arose, how the project was able to manage them. The report from the closing policy meeting "Future of mHealth in Europe Lessons learned from the EmERGE project" was published in Sept 2020.

List of meetings with the European Commission i :

 [PDF file](#)

List of contributions to public consultations i :

[Collapse/expand all contributions](#)

Pharmaceutical Strategy - Timely patient access to affordable medicines

Evaluation of the EU Drugs Strategy 2013-2020

Evaluation of the EU Drugs Strategy 2013-2020

List of contributions to roadmaps i :

N/A

Participation in EU structures and platforms

Intergroups and unofficial groupings (European Parliament) i :

N/A

Commission Expert Groups And Other Similar Entities (European Commission) i :

[Collapse/expand all memberships](#)

E02681 Commission expert group - Civil Society Forum on Drugs *Type C member*

Complementary information:

Achievements:

EATG has been at the forefront of community involvement in treatment development in HIV and co-infections. Our models of community involvement are shared with patient organisations beyond the HIV and co-infections field. EATG has been leading on innovative techniques such as biomedical prevention and HIV cure research.

EATG has been actively involved in setting up the EU Civil Society Forum on HIV, hepatitis and TB.

Currently we are playing a leading role in the reform of the CSF.

In 1997 EATG created the European Community Advisory Board (ECAB) to address key science and policy issues related to HIV and its main co-infections like hepatitis C or tuberculosis. Today and in the coming years, these ECABs will remain one of EATG's core activities. This model of high-level scientific platform has been copied by other national and international community groups and networks (e.g. Portuguese CAB, EECA CAB, TB CAB, Positive Council Switzerland etc.)

Via our 'Sitges' meetings, EATG has driven the community input in HCV cure development.

EATG provides capacity building to different stakeholders, thus supporting better networking (especially in Central and Eastern Europe), increased capacity of people living with HIV and health care providers, but also – via follow up activities – direct involvement of these people in new scientific and policy activities.

Population(s) served:

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. It 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.

Our members are representatives of different communities affected by HIV/AIDS in Europe. Our members are expert patients and treatment advocates coming from the WHO European region continuously working together to end the epidemic by advancing research on HIV/AIDS, broadening access to treatment, training/mentoring new HIV/AIDS advocates and ensuring that the patient Community is a permanent and highly-recognised voice in the research arena.

EATG has close links with groups and organisations within the area of sex work, drug use, MSM, migrants, prisoners etc. Our work is also in close collaboration with organisations that work on related topics such as vaccine development, prevention, liver disease, sexual health or human rights issues such as stigma and discrimination.

Involvement of people living with HIV :

EATG is a membership driven organisation. Our members are all members of the General Assembly (GA), the highest decision-making body of the EATG. A major part of our members are people living with HIV. The GA is called at least annually by the Board of Directors (BoD). The GA elects the members of the BoD and other bodies. Directors are elected for a period of two years.

HIV positive members are also represented within each part of the structure (selected via democratic systems): Programme Chairs; BoD members, staff and other internal positions. EATG has 3 Programme Areas: Quality of Life, Combination Prevention and Partners in Science. Members become active within one or more of the Programmes, as part of designated Programme Committees or ad hoc task groups. EATG regularly organises consultations with its members and other groups. We actively support the GIPA principle.

Members are the main drivers of our strategic development. With support from the office members, they draft our long-term strategy, set priorities etc. We have many HIV-positive members involved as representatives within different structures and positions such as steering committees, scientific committees, and advisory boards.

Number of persons involved in the activities described in the box above

Number of persons involved from the organisation expressed in % of working time:

100%: 0 75%: 0 50%: 0 25%: 6

Number of persons involved:

6

Full time equivalent (FTE):

1.5

Complementary information:

We are a voluntary organisation with over 150 members from over 45 countries within and outside Europe.

Our full-time Programme Manager works approx. 1/3 of her time on transparency register activities.

Persons accredited for access to European Parliament premises

First name	Surname	Start Date	End Date
Pieter	VANHOLDER	15/05/2020	31/05/2021
Ann Isabelle	von Lingen	13/05/2020	12/05/2021

Fields of interest

The organisation's fields of interests are:

- Education and training
- Justice and Fundamental Rights
- Public Health
- Research and innovation

Membership and affiliation

Total number of members that are natural persons:

154

Member organisations:

n/a

The organisation has members/is represented in the following country(countries):

- AUSTRIA

- BELGIUM
- BULGARIA
- CROATIA
- CYPRUS
- CZECH REPUBLIC
- DENMARK
- ESTONIA
- FRANCE
- GERMANY
- GREECE
- HUNGARY
- IRELAND
- ITALY
- LATVIA
- LITHUANIA
- LUXEMBOURG
- MALTA
- NETHERLANDS
- POLAND
- PORTUGAL
- ROMANIA
- SLOVENIA
- SPAIN
- ALBANIA
- ARMENIA
- BOSNIA-HERZEGOVINA
- CANADA
- GEORGIA
- ISRAEL
- KYRGYZSTAN
- MOLDOVA, REPUBLIC OF
- NORTH MACEDONIA
- RUSSIA, FEDERATION OF
- SERBIA
- SWITZERLAND
- TAJIKISTAN
- TURKEY
- UKRAINE
- UNITED KINGDOM
- UNITED STATES
- UZBEKISTAN

Membership of any associations/(con)federations/networks or other bodies:

EU Civil Society Forum (CSF) on HIV , TB and Hepatitis
 EU Civil Society Forum on Drugs
 WHO Regional Coordination Committee on HIV, TB and Hep
 AIDS Action Europe;
 European Public Health Alliance (EPHA);
 European Forum for Good Clinical Practice (EFGCP)
 European Patient Forum (EPF)
 Platform for Cooperation with undocumented migrants (PICUM)
 ILGA – Europe
 International Committee on Rights of Sex Workers (ICRSE)

Financial data

Financial year:

01/2020 - 12/2020

Estimate of the annual costs related to activities covered by the register:

25,000 € - 49,999 €

Total budget:

897,282 €

of which public financing:

222,670 €

Most recent financial information about funding received from the EU institutions:

Procurement:

€

Source:

Grants:

222,670 €

Source:

H2020 IMI

- from national sources:

€

- from local/regional sources:

€

from other sources:

674,612 €

- donations:

473,544 €

- contributions from members:

0 €

- recoverable costs :

392 €

- other projects :

189,344 €

- interest :

143 €

- membership fees :

4,950 €

- other :

6,239 €

Other (financial) information provided by the organisation:

 **Code of conduct**

By its registration the organisation has signed the Transparency Register Code of Conduct.