

Patient-led Innovations: Community Advisory Boards

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Session 7: Patients' organization-led innovation-what works? #GPC2016
Sat 9 Apr 1545-1630

1989-1991

- Rights of People living with HIV/AIDS
- ACT UP New York
- Treatment & Data Committee
- (US) AIDS Treatment Agenda

- AIDS & Medication Seminars
- European AIDS Treatment Agenda



- The European AIDS Treatment Group (EATG), founded in 1992, is a co-operative structure of people from different nationalities and communities affected by HIV/AIDS in Europe and elsewhere.
- The EATG is a registered charitable association (gemeinnütziger e.V.) under German law, with the Secretariate in Brussels, Belgium

Guiding Principles

- Be **democratic** and accountable, transparent and accessible to its members, people living with HIV, and their advocates
- Reflect in its membership the diversity of **people living with HIV and their advocates**
- Respect the **diversity** of people regarding considerations such as religion, gender, sexual preference and lifestyle.
- **Work** to complement and collaborate with other relevant groups
- Prioritize and regularly **evaluate its activities** according to its objectives, cost effectiveness, and fairness.

EATG Mission

"To achieve the fastest possible access to ***state of the art*** medical products and devices, and diagnostic tests that prevent or treat HIV infection or improve the quality of life for people living with HIV, or at risk of HIV infection. (...)"

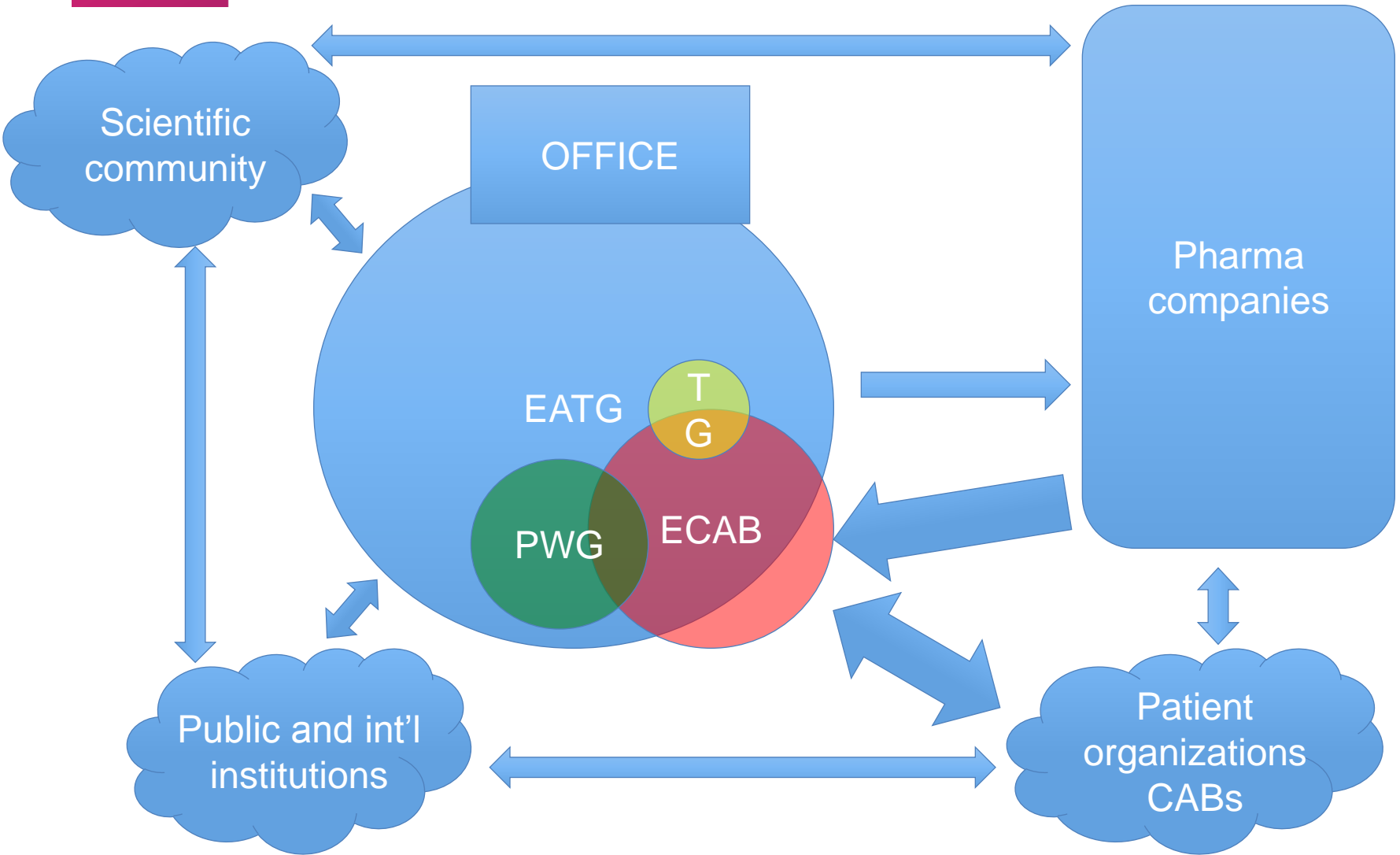


European
AIDS Treatment
Group

From Albania, Armenia, Austria, Belgium, Bosnia & Herzegovina, Bulgaria, Canada, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Kosovo, Kyrgyzstan, Latvia, Lithuania, Luxembourg, Macedonia, Montenegro, Netherlands, Poland, Portugal, Romania, Russian Federation, Serbia, Slovenia, South Africa, Spain, Sweden, Switzerland, Tajikistan, Turkey, Ukraine, United Kingdom, United States, Uzbekistan



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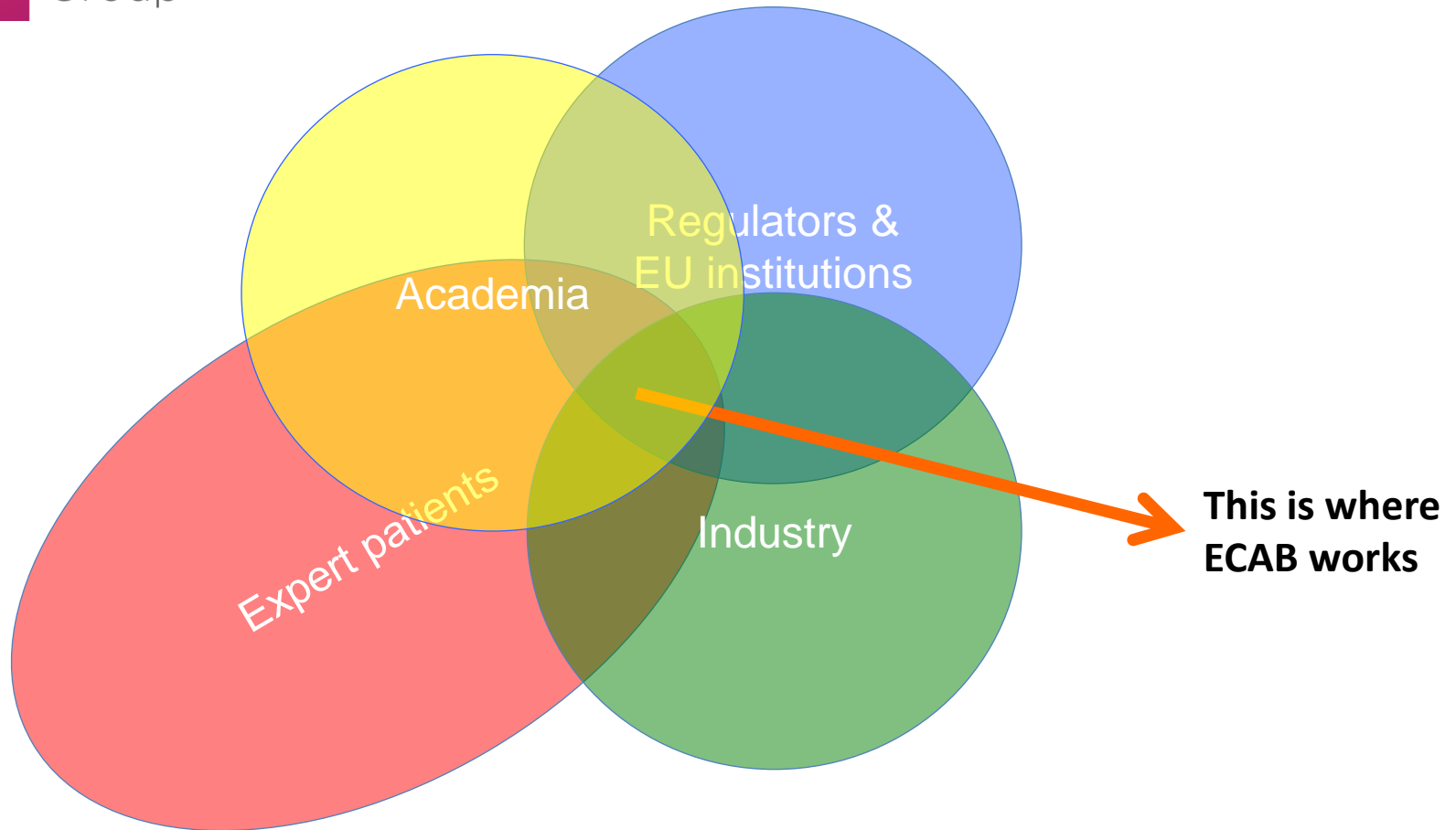


European Community Advisory Board

- 150 members (Working Group)
- regional (EU, WHO EURO 53)
- platform for Research and Development
- to address the issues of patients in clinical research



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ECAB can be seen, and positioned as, **a novel vehicle of innovation.**

ECAB Authority

- setting the agenda
- drawing participants
- establishing dialogue in a new order
- enabling training
- having an impact
- achieving results
- following-up on activities

Achievements

- changed trial designs and protocols
- monitored drug development
- participated in Data and Safety Monitoring Boards
- opened new avenues for research
- supported D:A:D study
- copied in Portugal, Spain, Russia, UK, Ukraine

Expansions

- Hep C and Tbc
- Diagnostics
- Biomedical Prevention
- Affordability
- STEP UP Academy
- EATG Focus on Ageing (50+, <25, 18-50)



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Networks

