European AIDS Treatment Group

For Immediate release

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Online premiere: documentary on inclusion of people living with HIV/HCV coinfection in clinical trials and access to hepatitis C new treatments

The European AIDS Treatment Group launches on January 25th, 2024 "*What We Wanted was What We Needed - Rebuilding a Community of Memories and Inclusive Advocacy*", a feature documentary on the Sitges Meetings. This documentary, filmed between September 30th and October 02nd, 2023 in Sitges, Spain, documents stories, experiences, results, and lessons learned from the Sitges meetings. This documentary happened within the framework of the Belong project, advocating for the inclusion of people living with HIV in non-HIV clinical trials.

The Sitges Meetings were a series of community-owned multi-stakeholder meetings, held between 2007 and 2017 in Sitges, Spain and organised by the EATG. The purpose was to promote the inclusion of people with HIV/hepatitis C (HCV) coinfection in clinical trials for emerging hepatitis treatments, and rapid access to new, safe and effective treatments.

When asked about the historical importance of the Sitges Meetings, **Joan Tallada, EATG Member and one of the initiators of the Sitges Meetings,** says: *"I have always thought that our main responsibility as activists is to keep people living with HIV alive. Back in the mid-2000s, we realised that in many European countries, after an exhausting struggle to ensure access to antiretroviral drugs, people living with HIV were dying again, this time from hepatitis C-related liver failure. We had to rise once more to change the rules, to make sure that people living with HIV were included in clinical trials of HCV antivirals before marketing authorisation and not after it. And we made it. Again".*

The Sitges meetings employed a **collaborative approach** to find concrete solutions, involving community representatives and activists from the HIV and hepatitis field, regulators, physicians, researchers and the pharmaceutical industry. Emphasising the urgency to find effective treatments supported by clinical trial data, the Sitges meetings raised awareness about HIV/HCV comorbidity. This led to **changes in exclusion criteria for clinical trials and revisions to the European Medicines Agency (EMA) guidelines.** These meetings set the ground for building meaningful connections between stakeholders, particularly within the HIV and hepatitis communities, as well as between the community, pharmaceutical companies and physicians.

As part of the Belong project, EATG conducted a Case Study that resulted into a written publication titled "What We Wanted was What We Needed" – A Model of Inclusive Community Advocacy: The Sitges Meetings, launched in December 2023 and a complementary documentary that sees the participation of **some of the main key actors** of the original Sitges Meetings,

namely, **Giorgio Barbareschi** (Belgium – EATG, Office), **Alessandra Cerioli** (Italy – LILA/ EATG), **Daniel De Schryver** (Germany - Janssen Pharmaceutica), **Diego García** (Spain - Sevilla Checkpoint/ EATG), **Filip Josephson** (Sweden - Swedish Medical Products Agency), **Luís Mendão** (Portugal - GAT/ EATG), **Jürgen Rockstroh** (Germany - University of Bonn), **Tracy Swan** (US/Spain - Independent Consultant) and **Brian West** (Scotland – EATG).

As **Brian West, Chair of EATG Partners in Science Programme,** highlights: *"The Belong project is important to people living with HIV. More and more of us are living with other co-morbidities, and it is vital that we are included in clinical trials of drugs that we will be using one day. The documentary filming highlighted this in a very personal way and gave a human face to this important topic".*

With the filming of this documentary, EATG wanted to capture and preserve an important moment of the history of the organisation advocacy, while reflecting on community needs and drawing lessons from effective community advocacy that can influence policies and clinical trials at a broader level. In addition, EATG aims to foster discussions that encourage all people with a health condition to assert their right to participate in clinical research, potentially benefiting their treatment and care.

In relation to the experience of the film production, **Rocco Pignata, EATG Project Coordinator**, shares, *"This documentary is a collage of stories and voices, a celebration of community unity and determination. Our commitment with this production was to put community first, bring people back together to where it all started and recreate that space of connection and conviviality that characterised the Sitges Meetings. We decided not to use scripts; instead, we wanted people to sit with us and walk us through their story of the Sitges Meetings in the language they preferred. And coordinating the production of this documentary was an amazing journey".*

In addition, **Apostolos Kalogiannis, EATG Communication Manager,** says: *"Our bet with this film was to recreate memories from a flagship long-standing EATG venture. Its lasting impression has remained vivid mainly via oral stories from people who played a role in the meetings. We knew that we had to preserve these narratives in a more systematic as well as approachable way. By the end of the filming, we were convinced that this body of stories carried such historical gravity beyond the memories that we felt compelled to share with everyone interested in the history of community advocacy to as full an extent as possible".*

EATG intends to replicate and apply the **Sitges Meetings Model** specifically to the development of guidelines for the inclusion of people living with HIV in non-HIV clinical trials. In considering the application of the Sitges Model to other disease areas, EATG's work underscores the importance of identifying the right community leaders and having all available scientific information to hand. The facilitation of meetings must seek a co-creation of solutions, with all people contributing to reach an agreement. The Sitges meetings demonstrated the power of combining two groups of patients/advocates (HIV and hepatitis) working alongside other key stakeholders towards a shared vision and to achieve stated goals.

The documentary premieres online on EATG YouTube Channel (@EATGMedia) on 25 January 2024 at 20.00 CET. It will be available for free online streaming for one month.

Join the premiere here: https://youtu.be/44LUd1EsJyI

For more information on Belong, visit the project page here: https://www.eatg.org/projects/belong/

With Inclusion, We #Belong

#TheSitgesMeetings

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For more information, please contact: communication@eatg.org (c/o Apostolos Kalogiannis)

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 (PLHIV) in Europe as well as those affected by HIV/AIDS and co-infections. For more information, please visit www.eatg.org