



Alpha-1 Europe Alliance

ACTIVITY REPORT 2025

2025: Seven workstreams



Governance & Organisational Capacity

Build a sustainable and resilient Alliance through strong governance, internal policies, and diversified resource development.



Community-Building & Patient Group Support

Strengthen the Alpha-1 patient community by providing learning opportunities, facilitating collaboration, and ensuring regular engagement with members.



Representation of the European Alpha-1 Community

Ensure the voice of the Alpha-1 community is heard by participating in key scientific forums and strategic multi-stakeholder groups.



Political Advocacy

Advance policy change through a defined advocacy roadmap, stakeholder engagement, and targeted EU-level outreach.



Communication & Dissemination

Enhance visibility and cohesion through a strong online presence, consistent branding, and clear messaging across channels.



Awareness building

Raise public and stakeholder awareness of AATD through dedicated campaigns and collaboration on broader awareness initiatives.



Research & Care Pathway

Foster scientific progress and improved care by ensuring the voice of people with AATD is embedded in research initiatives, thought leadership, and expert collaboration.

2025: Governance & Organisational Capacity (1/2)

Planned activities

- AGA
- Board
- Working Groups
- Support Team
- Resource Development
- Financial & in-kind Contributors

Implemented activities

- 3rd AGA Held online 17 June 2025
- Board Meetings twice monthly
- Working Groups Operational
- Support Team expanded: Flaminia Macchia (Advocacy) joined Lila Martinez Ucha (Communications) and Jill Bonjean (Coordination)
- Sustained funding base, monetary & in-kind





2025: Governance & Organisational Capacity (2/2)

The Alpha-1 Europe Alliance aims to coordinate and engage members via working groups, to benefit from expertise and volunteer commitment of our Member representatives while strengthening Alpha-1 patient organisation network. **Working group volunteers in 2025:**

Communications

- C Barbiero (Italy), E Goyanes Vilar (Spain), T Jones (UK), A Lemos (Portugal), AK Siegl (Germany)

Community-building & Patient Group Support

- S Beitz (Austria), R Ewals (the Netherlands), K Schmid (Switzerland), K Skaar (Nordics) F Willersinn, MD (Belgium)

Political Advocacy

- F Aspilche Ferro (Belgium), A Lemos (Portugal), AM O'Dowd / T Carroll, PhD (Ireland)
F Willersinn, MD (Belgium), H Stutzenberger, PhD (Germany)

2025: Community-building & Patient Group Support (1/2)

Planned activities

- Upskilling Activities
- Prepare Membership Meeting 2026
- Regular updates on relevant news & learning opportunities
- Exploration of Knowledge Hub

Implemented activities with Our Members

13

Member organisations

14

Countries represented

>90%

Alpha-1 organisations

4.500

People with AATD



2025: Community-building & Patient Group Support (2/2)

The Alliance is committed to empowering patient advocates and national organizations through dedicated training and development programs. Capacity-building in 2025 included:



Webinar on DNA & RNA

- with Marion Bouchecareilh, PhD
- 69% of Members attended
- All rated the event high quality and useful



EFA* Respiratory Patients Academy

- 4-day intensive training in Prague (Nov 13-16)
- Five Member Representatives attended

*European Federation of Allergy and Airways Diseases Patients' Associations.



Monthly Members Meetings

- held throughout the year to inform Members of Alliance actions and receive input from Members' perspective.
- Peer-to-Peer training: Volunteer Management presented at November Monthly Members Meeting





2025: Representing European Alpha-1 Community (1/2)

Planned activities

- ERNs Lung & Liver
- Research Conference & Patient Congress Lisbon
- EURORDIS Members Meeting
- International Plasma Protein Congress
- European Respiratory Society Conference
- European Lung Foundation
- Meetings with industry

Implemented activities

The Alliance is an active partner with key European health networks and organizations to amplify advocacy efforts, exchange knowledge, and drive policy change. Our participation in 2025 included:

ePAG of ERN Lung & ERN Liver	Member of: European Lung Foundation, EURORDIS	Represented at EARCO via Board Member & Member Representative
Standing monthly meetings with Alpha-1 Foundation	Meetings with industry throughout the year	Eurordis Black Pearl Awards
Alpha-1 Congress Lisbon April 2025	IPPC 2025 May Warsaw	Eurordis Membership Meeting 2025 May Riga
ERS Breathing Better event at European Parliament (September)	European Respiratory Society (27 Sep- 1 Oct, Amsterdam)	Alpha-1 Foundation meeting at European Parliament (November)



2025: Representing European Alpha-1 Community (2/2)



EURORDIS Black Pearl Awards



A1F Congress Lisbon



IPPC 2025



EURORDIS EMM 2025 Riga



13-16 November | Prague



European Parliament



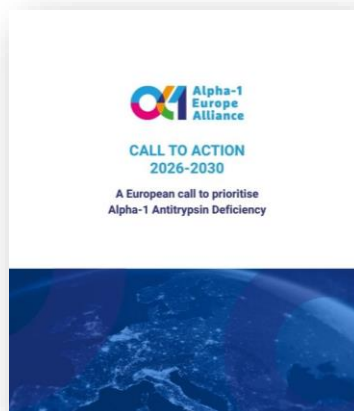


2025: Political Advocacy (1/2)

Planned activities

- Event Report & Calls to Action
- Stakeholder mapping
- Political Advocacy strategy
- EU outreach Brussels
- Plasma supply campaign strategy

Implemented activities



This **Call to Action** unites the Alpha-1 community around six priorities to tackle urgent care gaps, reduce inequalities, and advance a fairer future for all.

- 1 Recognise the needs of people with Alpha-1 Antitrypsin Deficiency (AATD)**
AATD is a rare genetic condition that may lead to severe lung, liver or skin diseases. As reflected by its unique ORPHAcode (60) and inclusion in the International Classification of Diseases (E88.01), AATD requires specific expertise, therapies and care. We call for the recognition of the specificities of the condition and the needs of people with AATD. We therefore urge EU policymakers to prioritise AATD within initiatives for rare diseases, lung, liver and skin diseases.
- 2 Enable early, accurate and targeted diagnosis of AATD across Europe**
Given its specificities, it is particularly challenging to ensure timely diagnosis of AATD. We call for the development of a European-wide strategy promoting targeted access to early and accurate diagnosis, especially for patients with COPD, severe asthma that is difficult to treat, bronchiectasis, unexplained liver disease, panniculitis, vasculitis and family history of Alpha-1.
- 3 Ensure equitable access to treatments and therapies**
Access to treatments remains highly fragmented and deeply unequal in Europe. Today, only 12 EU Member States fully reimburse augmentation therapy. To close this gap, we call for dedicated funding for AATD therapies, including the establishment of dedicated national or regional funds for AATD, accelerated access pathways, specific reimbursement systems, early access programmes and innovative access schemes.
- 4 Build a sustainable and ethical plasma supply in Europe**
Currently, only 4 EU Member States – Austria, Germany, Czechia, and Hungary – meet their plasma needs without relying on imports. To reduce EU dependency on non-EU plasma and manage rising demand, we call on EU Member States to allow and support donor compensation, in accordance with the principle of voluntary, unpaid donation, based on transparent criteria to be established in national legislation, as provided by SoHo Regulation (EU) 2024/1938. We also call on the EU institutions to bolster the current ecosystem by establishing a robust mechanism for public and private plasma collection that upholds a dual-ethics approach minimising any risk for plasma donors and assuring availability of plasma derived medicines for patients.
- 5 Invest in long term funding for public research in AATD**
We urge the EU to support the search for a cure for AATD through long term funding for public research in AATD within Horizon Europe, including ERD-ERA, and the EU4Health programme. We urge EU policymakers to maintain funding and strengthen collaboration between ERN-LUNG, ERN RARE-LIVER and ERN-Skin, the Alpha-1 patient community and the European Alpha-1 Research Collaboration (EARCO). Enhancing these partnerships will advance knowledge on the condition, help centralise critical information and improve patient referrals.
- 6 Embed patients in decision-making across policy, research, and health systems**
Patient communities offer vital expertise that should inform health policy decisions. We call on EU and national authorities to systematically involve AATD patients and organisations in therapy assessments – both at the EMA and within national HTA processes – and to ensure that the full socioeconomic impact on patients, caregivers, and society is reflected in all value and funding decisions.

Together, we're shaping a European strategy for better care and access by 2030.



With the Call to Action in place, the next Advocacy Objectives for 2025 were:



Strategic
advisory support



Stakeholder
mapping



Development of
political advocacy
strategy



Building
partnerships &
alliances



2025: Political Advocacy (2/2)



- September: attended *Breathing Better: Scaling up EU prevention policies for respiratory health* at the European Parliament hosted by MEP Romana Jerković and Prof. Silke Ryan, President of ERS.
- November: Fernanda and Flaminia presented at International *Alpha-1 Awareness Month* event hosted by MEP Olivier Chastel
- The Alliance Leveraged this success by securing a meeting with MEP Chastel's office, held in January 2026.



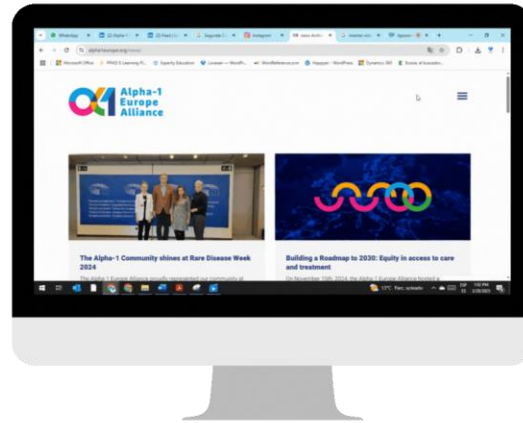
2025: Communications & Dissemination (1/2)

Planned activities

- Update & enlarge website
- Create Corporate Materials
- Build Social Media
- Launch Newsletter
- Highlight participation in events



Implemented activities



- Corporate videos (3)

- Continuous content updates

- Website: News section

 **17 articles**

 **Traffic (organic growth)**

- 5.922 visits
- Average time on site: 1:17 minutes.

From: connect-noreply@alpha1europe.org
Subject: Alpha-1 Europe Voices | February 2026
Preview: Stay connected with the Alpha-1 Europe Alliance Newsletter – the voice of Alpha-1 patient organisations across Europe, sharing news, updates, and community stories.



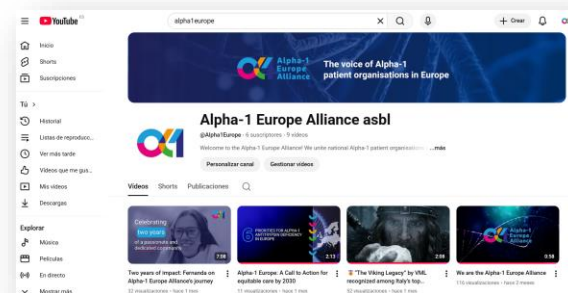
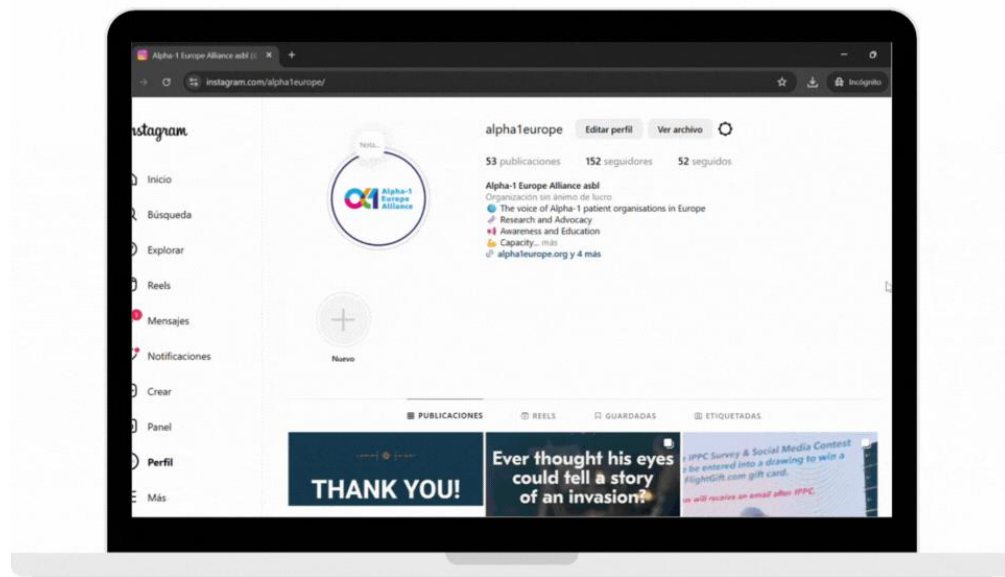
- Newsletter launch (Dec 2025)





2025: Communications & Dissemination (2/2)

- Social media planning (campaigns, events coverage, community engagement)



Follow us on
 YouTube

- Youtube channel launch



Campaigns	#
• A1EA Institutional	5
• AATD Awareness	4
• Events & News	8
• Key dates	9

616 followers
↑ 110% increase

106 followers
↑ 146% increase

316 followers
↑ Growth over the last 12 months.

287 followers
↑ Growth over the last 12 months.



- Corporate materials

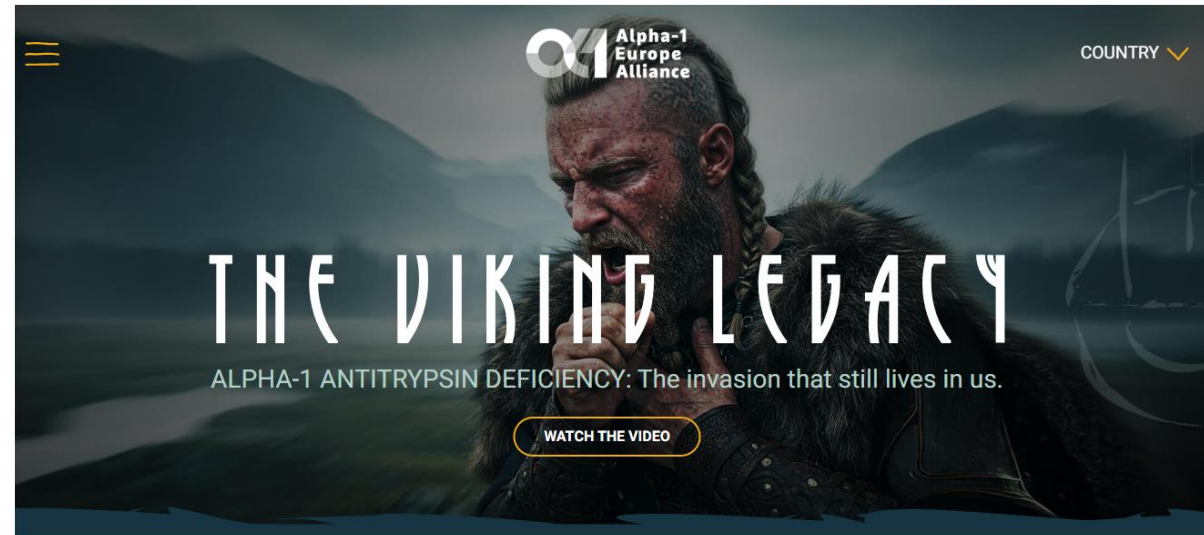
2025: Awareness-building

Planned activities

- European Alpha-1 Awareness Day
- Rare Disease Day
- International Plasma Awareness Week
- Other related Awareness Days

Implemented activities

2025 Campaign: The Viking Legacy



Rare Disease Campaign



IPAW 2025 (multilanguage)



2025: Research & care pathway

Planned activities

- Application ERDERA project
- Preparation to Launch Medical Advisory Board
- EMA application as eligible stakeholder
- Thought leadership: support of EURORDIS / EPF Call for patient voice embedded in EMA decision-making
- Advisory meetings with industry

Implemented activities

The Alliance advanced toward becoming an EMA eligible organisation by:



Preparing financials for FY 2024 and undergoing audit for 2023-2024



Developing and ratifying with Members our *Policy on Transparency and Integrity in Funding*



Developing a *Transparency* section of alpha1europe.org

Thank you!



The background features a dark blue map of Europe. Four large, semi-circular arcs in orange, green, magenta, and light blue are positioned around the map. The text "THANK YOU" is centered in white.

THANK YOU

