Alpha-1 Europe Alliance

ACTIVITY REPORT 2025

2025: Seven worksteams

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.

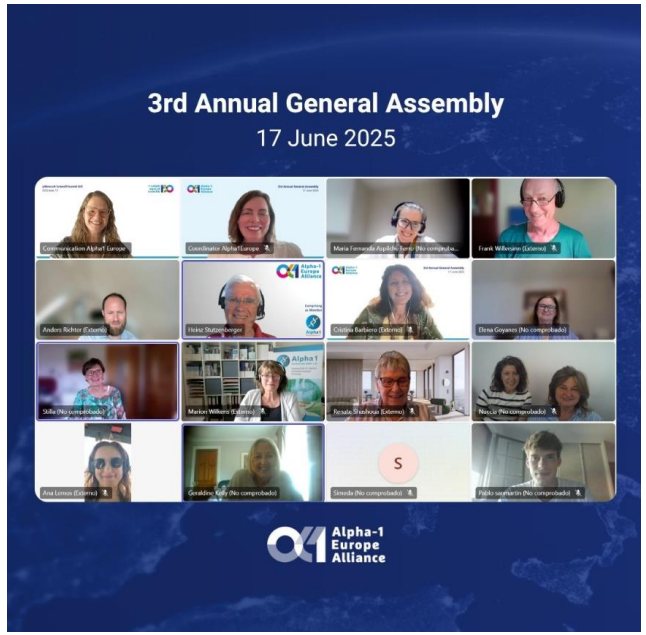
2025: Governance & Organisational Capacity (1/2)

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

European RESPIRATORY PATIENT Academy

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

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

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)

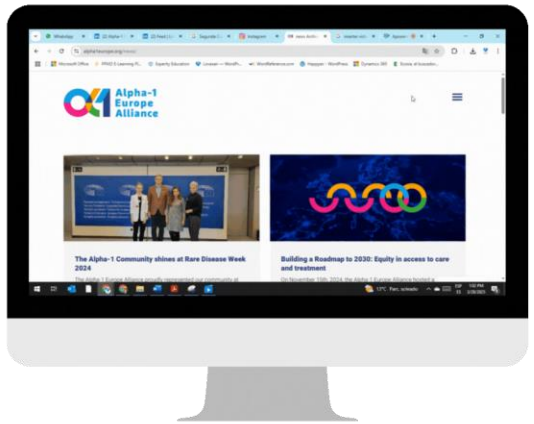
- September: attended *Breathing Better: Scaling up EU prevention policies for respiratory health* at the European Parliament hosted by MEP Romana Jerković and Prof. Silke Ryan , President of ERS.
- November: Fernanda and Flaminia presented at International *Alpha-1 Awareness Month* event hosted by MEP 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



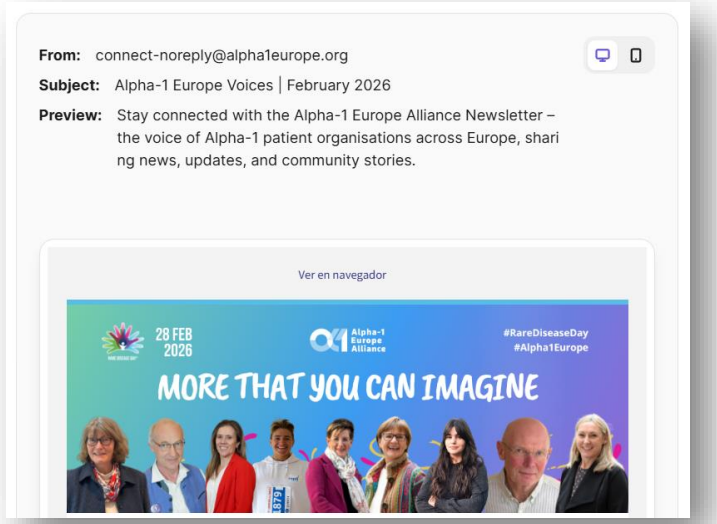
- Continuous content updates
- Website: News section

17 articles

- Corporate videos (3)

Traffic (organic growth)

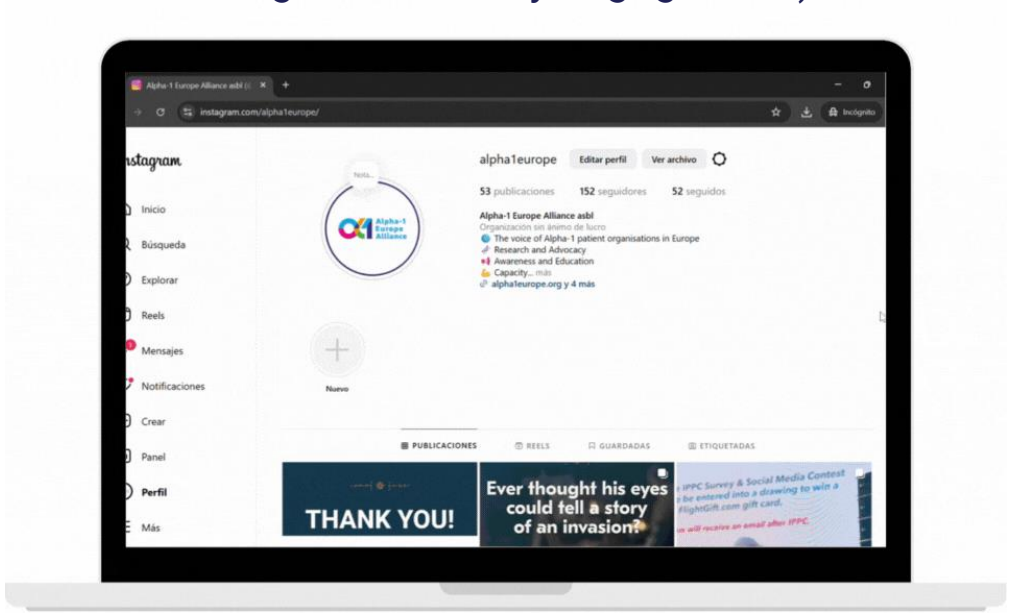
- 5.922 visits
- Average time on site: 1:17 minutes.



- Newsletter launch (Dec 2025)

2025: Communications & Dissemination (2/2)

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



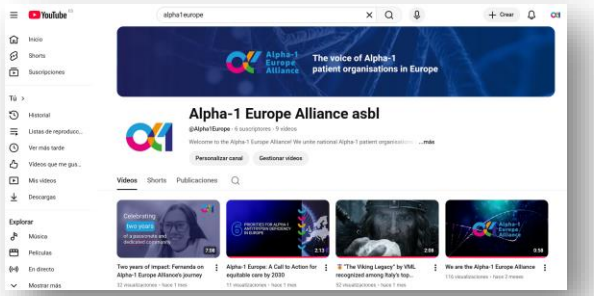
Campaigns	#
• A1EA Institutional	5
• AATD Awareness	4
• Events & News	8
• Key dates	9

616 followers
↑ 110% increase

106 followers
↑ 146% increase

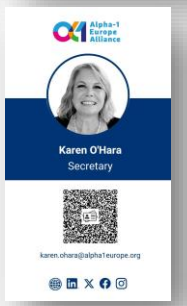
316 followers
↑ Growth over the last 12 months.

287 followers
↑ Growth over the last 12 months.



Follow us on YouTube

- Youtube channel launch



- Corporate materials

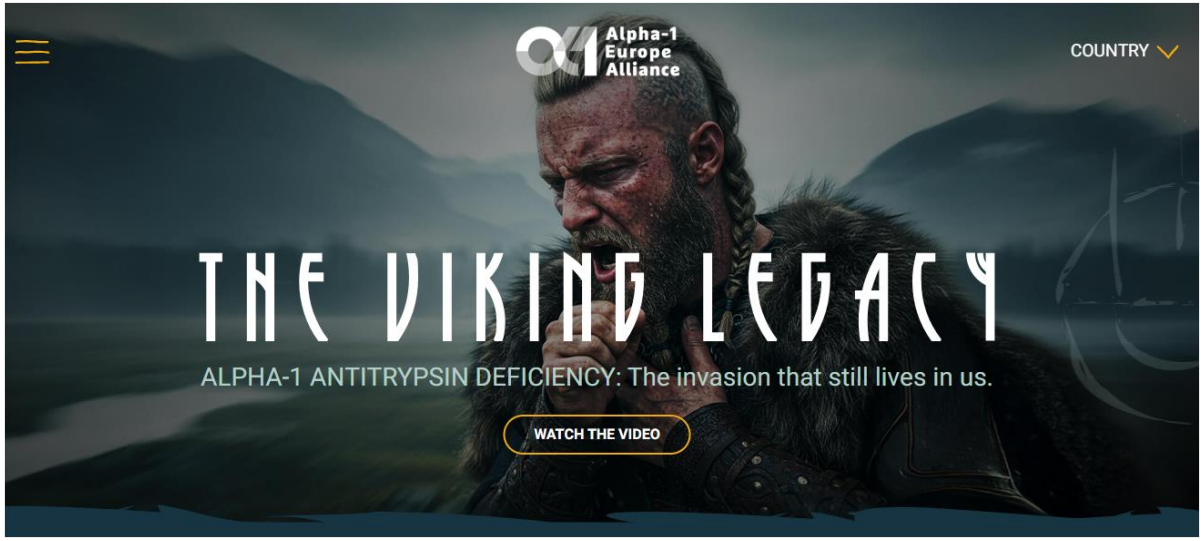
2025: Awareness-building

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!


Alpha 1
ÖSTERREICH gem.V.


alpha-1Plus
BELGIUM


Alpha 1
Deutschland e.V.


ALPHA-1
FOUNDATION
IRELAND


ASSOCIAZIONE
AT
ODV


LONG
FONDS


ALFA-1NORDEN


AAIP
Associação Alfa1 de Portugal


ASOCIATIA
ALFASIM


alfa1
ESPAÑA


Lovexair
Foundation
care for your lungs


alpha-1
VEREIN SCHWEIZ


Alpha 1 UK


THANK YOU
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