

Introduction to the Alpha-1 Europe Alliance



Our History



Our History

- idea to intensify information exchange was born during the COVID-19 pandemic
- leaders of European Alpha-1 patient organisations decided to meet monthly online to exchange ideas and share experiences
- monthly meetings began to be used to fill informational needs in the community
- from the concept of the monthly meeting, it was a natural leap to establish an official organisation to continue and broaden the scope of this collaboration in a more formalised manner
- decision to form an umbrella organization in early 2022
- prep work started late 2022
- Alliance founded on 17.10.2023 with seat in Brussels
- first General Assembly on 27.11.2023 in Barcelona



Why we exist



All people living with Alpha-1 in Europe experience a better and longer life through a holistic approach to Alpha-1 with access to the best possible present and future treatment, and ultimately a cure.



What we do



01 REPRESENT ALPHA-1 PATIENT COMMUNITY AT THE EUROPEAN LEVEL



02 ADVOCATE FOR ACCESS TO DIAGNOSIS, TREATMENT AND CARE



03 FOSTER RESEARCH TOWARD A CURE



04 SERVE AS POINT OF CONTACT FOR RESEARCH AND DEVELOPMENT



05 RAISE AWARENESS AND EDUCATE ALL STAKEHOLDERS



06 SUPPORT NATIONAL ALPHA-1 ORGANISATIONS



Who we are



Our members

- Regional, national or international organisations working in Europe that support people affected by alpha-1 and associated diseases
- Other organisations and individuals interested in supporting our advocacy efforts in regions with no established organisations



Alpha-1 Europe Alliance Coverage September 2024

- 13 members
- 14 countries
- >90% Alpha-1 organisations
- representing 4400 patients



Our member organisations



Our Board

**Fernanda
Aspilche
Ferro**

President



**Heinz
Stutzenberger,
PhD**

Vice-President



**Elena
Goyanes
Vilar**

Treasurer



**Karen
O'Hara**

Secretary



**Frank
Willersinn,
MD**

Board member



**Cristina
Barbiero**

Board member



Our Supporters



Jill Bonjean


Executive
Consultant



**Lila Martinez
Ucha**

Communication
Manager

Our Channels



Alpha-1 Europe Alliance

Our Work

At Alpha-1 Europe Alliance, we strengthen the European Alpha-1 patient community through research, advocacy, awareness, education and capacity building.

[Learn more](#)



Our work



Alpha-1 Awareness Campaign



European Alpha-1 Awareness Day

European Alpha-1 Awareness Day

#unitedforalpha1

An initiative of the Alpha-1 Europe Alliance to raise awareness about the disease alpha-1 antitrypsin deficiency.

#unitedforalpha1

Let's join forces and address the unmet needs of alpha-1 patients in Europe!

European Alpha-1 Awareness Day

Not knowing isn't immunity.

#unitedforalpha1

About 90% of Alpha-1 patients remain undiagnosed throughout their lives.

Only 7 out of 100 alpha-1 patients receive a timely diagnosis.

#unitedforalpha1

Early detection can improve lives.

Not as rare as you think.

#unitedforalpha1

Up to 3% of COPD cases are linked to alpha-1 antitrypsin deficiency.

The most common genetic cause of children's liver transplants is alpha-1.

#unitedforalpha1

A rare disease, that's not so rare at all.

Not a luxury, but a right for all.

#unitedforalpha1

Championing equal access to alpha-1 treatment across Europe.

Support doesn't end with disease treatment.

#unitedforalpha1

Advocating for access to holistic alpha-1 care in Europe.

Strength through unity: Raising awareness for the alpha-1 patient community.

#unitedforalpha1

Join your national alpha-1 association today - because every voice matters.



#unitedforalpha1

- **8 posts** encouraging testing and calling for equitable access to care and treatment
- **13 languages** (English, German, French, Italian, Spanish, Portuguese, Romanian, Flemish, Danish, Dutch, Swedish, Norwegian, Polish)
- **17 organisations** across Europe involved in the message translations and validations (11 Alliance members + 6 friends)

Campaign organizational participants

(posted on social media about awareness day)

A1EA members



A1EA friends



Other community members



+ several individuals posted and interacted with posts across platforms

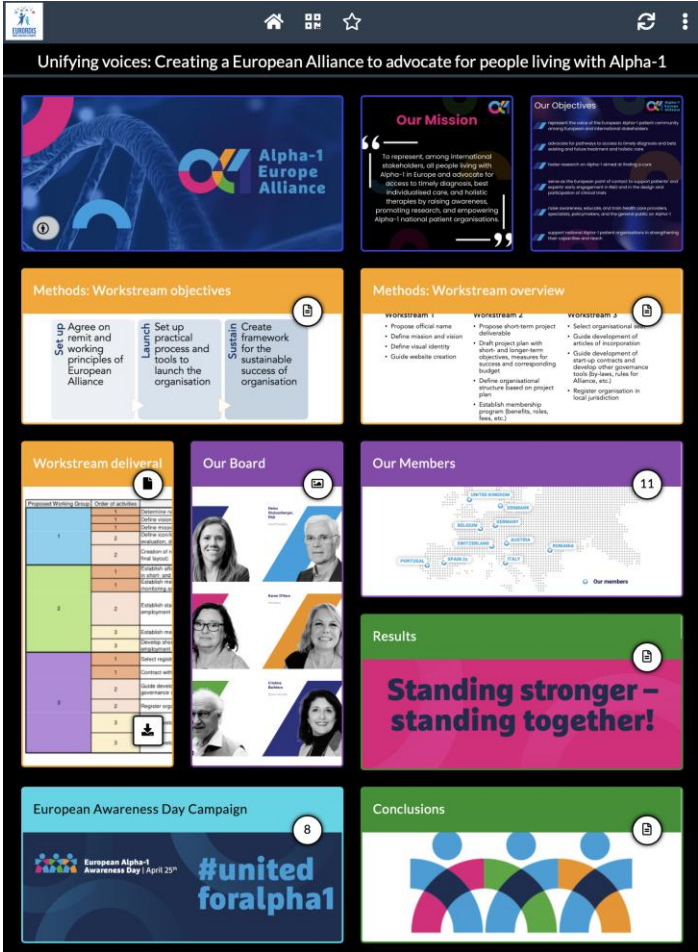
Over 20 organisations globally actively posted the campaign materials or referenced the campaign across LinkedIn, Facebook, Instagram, and X

Thought leadership: Publication of efforts

Poster at European Conference on Rare Diseases (ECRD) 2024

Publication of abstract in Orphanet Journal for Rare Disorders

Alpha-1 Europe Alliance



“On behalf of EURORDIS-Rare Diseases Europe and the ECRD 2024 Poster Committee, we are delighted to inform you that your poster *Unifying voices: Creating a European Alliance to advocate for a better and longer life for people living with Alpha-1* is among the top scoring posters for this conference.

As a result, we would like to offer you a unique opportunity to submit an abstract of your poster for publication in The Orphanet Journal of Rare Diseases (OJRD) via EURORDIS. It will be a special supplement published later this year, featuring abstracts from speakers and top scoring poster presenters at the ECRD 2024 hybrid conference.”





Thank you

www.alpha1europe.org