APACS
Associazione Pazienti Sindrome di Churg Strauss

Position Paper: Establishing a European EGPA Foundation

Executive Summary

Eosinophilic Granulomatosis with Polyangiitis (EGPA) is a rare, severe autoimmune vasculitis, with an incidence of **0.5–4.2 cases per million annually** and a prevalence of **10–14 cases per million globally** [1].

Unlike other vasculitides — and even compared with other ANCA-associated vasculitides (AAVs) such as granulomatosis with polyangiitis (GPA) and microscopic polyangiitis (MPA), EGPA has a **distinct pathophysiology**, combining **eosinophil-driven inflammation** with small- and medium-vessel vasculitis. Eosinophilia is present in almost all patients, often >1,500 cells/µL, together with asthma and allergic features [1,5]. This dual mechanism distinguishes EGPA from GPA and MPA, which are predominantly neutrophil/ANCA-driven [1].

Clinically, EGPA presents a unique profile:

- **Asthma** in over 90% of patients, typically adult-onset [1].
- **ENT involvement** (chronic rhinosinusitis, nasal polyps) in 60–80% [2].
- **Neurological** (50–70% with peripheral neuropathy) and **cardiac manifestations** more frequent than in other AAVs [1].
- **Relapse rates** exceeding 50% in the first year after diagnosis [3].

Therapeutically, EGPA also differs from other AAVs. Corticosteroids remain the mainstay of treatment, but long-term dependence is common. Immunosuppressants widely used in GPA/MPA are not always effective, especially in ANCA-negative patients [1]. Biologic therapies targeting eosinophils have transformed the landscape:

- **Mepolizumab** has shown efficacy in relapsing and refractory EGPA [1,6].
- **Benralizumab** has recently been demonstrated to be noninferior to mepolizumab for induction of remission at 36 weeks [7].
- Real-world data confirm that biologics reduce corticosteroid dependence and sustain remission [6].

Yet **access to biologic therapies remains unequal across Europe**, leaving many patients reliant on corticosteroids with significant morbidity [1,2]. These differences in pathophysiology, clinical course, and therapeutic needs underline the necessity for **disease-specific strategies and advocacy**, distinct from those applied to other AAVs.

Currently, patient representation and research on EGPA remain fragmented across countries, with significant disparities in standards of care. The creation of a **European EGPA Foundation** would address these gaps by:

- **Uniting patient voices** across Europe under transparent, patient-centered governance.
- **Promoting collaborative research** to accelerate innovation and improve clinical outcomes.
- **Advocating at EU level** to secure equitable access to diagnosis, treatment, and care.
- **Supporting national initiatives**, while creating a European hub of expertise and advocacy.

Importantly, the Foundation will **not be a federation**. Membership will not require the existence of national EGPA associations. Instead, it will provide a European platform open to individual patients, caregivers, professionals, and groups. Where national associations exist—or where patients wish to create or expand them—the Foundation will offer support and visibility, without imposing structural obligations.

This initiative, promoted by APACS with the European EGPA Study Group (EESG) as scientific pillar, follows successful models such as the European Lung Foundation. It will ensure **balanced governance, patient leadership, and scientific excellence**, ultimately improving outcomes for EGPA patients across Europe.

Why a European EGPA Foundation

EGPA is increasingly recognized as distinct from other ANCA-associated vasculitides, both scientifically and clinically [1]. Its rarity and complexity demand a dedicated European structure.

A European EGPA Foundation would:

- Strengthen cross-country patient representation.
- Provide a transparent and inclusive governance model.
- Enable high-level advocacy with EU institutions, agencies, and policymakers.
- Attract greater funding for research and innovation.
- Support national and local patient initiatives, fostering collaboration across Europe.

Our reference model is the **European Lung Foundation**, where governance is shared between patient and professional representatives under a trusted European framework [4].

Legal and Economic Considerations

The Foundation will be established under European law, with its registered office in Italy.

According to Italian legislation, the creation of a recognized foundation requires a minimum endowment of **EUR 30,000**, provided in cash or assets. This guarantees financial solidity and independence from inception.

Additional funding will be sought through European programs, institutional partnerships, research grants, and collaborations with industry—always under principles of **transparency** and **accountability**.

Governance Model

We propose a hybrid governance structure, ensuring both stability and inclusivity:

- **Founding Members (APACS and partners):** nominate an initial Board of Directors to guarantee continuity, expertise, and patient-driven leadership.
- **Stakeholder Representatives:** patient groups from other countries, scientific bodies (EESG), institutions, and industry may join through formal nomination or agreement.
- **General Assembly:** all members (patients, associations, experts, institutions) form a forum for transparency and consultation.
- **Board of Directors:** mixed composition of founders and stakeholders, initially chaired by APACS for a 3–5 year transition phase.
- **Scientific Board:** the European EGPA Study Group, ensuring scientific rigor and independence.
- **Advisory Councils:** thematic working groups (research, empowerment, advocacy, communication).

This **hybrid model** guarantees:

- **Patient-centered** leadership.
- **Transparency** and shared decision-making.
- **Independence** from specific interests.
- **Gradual inclusion** of new national EGPA groups.

Notably, the Foundation will not be a federation. Individual patients, caregivers, and professionals may join directly, without requiring a national association. However, when national groups exist—or when patients wish to establish them—the Foundation will act as a **supportive and enabling partner**.

Position on Other International Organizations

We recognize the contributions of international organizations active in vasculitis, and we welcome their endorsement and collaboration.

However, the mission of the European EGPA Foundation is **distinct**. EGPA presents specific clinical, scientific, and patient challenges that require a **dedicated, disease-focused structure**. For this

reason, leadership of the Foundation must remain **with the EGPA patient community**, with APACS as promoter and EESG as the scientific pillar.

While we welcome collaboration, endorsement, and exchange of best practices with international organizations, the governance of the Foundation will be **purposefully focused on EGPA alone**. This ensures complementarity with wider vasculitis initiatives, while safeguarding the clarity of our mission. This ensures:

- **Clarity of mission** – focused exclusively on EGPA.
- **Credibility** – rooted in lived patient experience and scientific evidence.
- **Independence** – free from competing priorities across other vasculitis subtypes.

In this way, the Foundation remains open to constructive partnerships, but firmly centered on its role as the **legitimate European voice for EGPA patients**.

Mission of the European EGPA Foundation

The Foundation's mission is to **improve the lives of people with EGPA** through empowerment, research, advocacy, and cross-country collaboration.

Strategic Objectives:

- Represent EGPA patients at the European level.
- Promote and support research and clinical collaboration.
- Advocate for equal access to diagnosis, treatment, and care.
- Educate patients, caregivers, healthcare professionals, and policymakers.
- Support and encourage national EGPA patient groups.
- Collaborate with academia, institutions, and industry under transparent governance rules.

In doing so, the Foundation remains **inclusive of all patients and stakeholders**, regardless of whether national associations exist in their country.

Conclusion

The establishment of a **European EGPA Foundation** is both timely and necessary. EGPA differs clinically and scientifically from other ANCA-associated vasculitides, and its unique challenges demand a structure dedicated exclusively to this disease [1–3].

By ensuring patient-led governance and drawing on the expertise of the European EGPA Study Group, the Foundation will become a **credible European hub for advocacy, research, and education**. It will reduce fragmentation, promote equal access to care, and amplify the patient voice at the EU level.

Crucially, the Foundation is **inclusive**: it does not require national associations but will empower and support them where they exist or wish to be created. This guarantees that all EGPA patients, regardless of geography, are represented and supported.

We call upon **policymakers, clinicians, researchers, patient advocates, and industry partners** to endorse and engage with this initiative. Together, we can transform the European landscape for EGPA, ensuring that patients no longer face isolation and inequity, but instead benefit from a **united**, **transparent**, and **scientifically grounded movement**.

References

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Proposed by

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Signed and Endorsed by APACS's Scientific Board