

Executive Summary

In 2025, Vasculitis International consolidated its position as a key European umbrella organisation for vasculitis patient groups. **Guided by the Strategic Plan 2025–2027**, our activities focused on four strategic pillars: **Encourage and Support, Develop Products and Services, Expand the Network, and Strengthen the Internal Organisation.**

A central highlight of the year was the establishment of a Czech patient group and subsequently the successful organisation of the 3rd European Vasculitis Patient Summit in Prague, bringing together 60 patient representatives, clinicians, and specialist nurses from 16 countries. The Summit has now become an established and recognised platform for knowledge exchange, collaboration, and capacity building within the European vasculitis community.

Throughout 2025, Vasculitis International actively supported the creation and strengthening of national patient organisations, notably in the Czech Republic and Germany. We invested in sustainable infrastructure by developing multilingual digital platforms and practical organisational tools, enabling patient groups to better support their communities.

Our network expanded further with the inclusion of new member organisations, strengthened relationships with medical and research partners, and exploratory initiatives in several countries without established patient representation. Despite operating with a small, volunteer-driven structure, Vasculitis International delivered significant impact and laid a solid foundation for continued growth, product development, and internal strengthening in 2026.

The generous grant support provided by our partners has been instrumental in enabling the activities described in this report. Through careful financial stewardship and a strong reliance on volunteer contributions, Vasculitis International consistently delivered its projects well within budget. This prudent approach provides a solid basis for organisational continuity over the next three to five years.

Introduction

The year 2025 has been a busy and successful year for Vasculitis International. Building on our Strategic Plan 2025–2027, we focused our activities on four strategic pillars:

1. Encourage and Support
2. Develop Products and Services
3. Expand Our Network
4. Strengthen Our Internal Organisation

This report provides an overview of our key activities and achievements in 2025, assessed against these strategic objectives.

Encourage and Support

Vasculitis International continued its efforts to bring together patient representatives, healthcare professionals, and researchers across Europe.

European Vasculitis Patient Summit

Following the success of the first international meeting on unmet needs of patients with ANCA-associated vasculitis (AAV) in Madrid (2023), and the 2nd European Vasculitis Patient Summit held in the Netherlands in 2024, we organised the **3rd European Vasculitis Patient Summit** in 2025.

The 2025 Summit took place in **Prague**, in collaboration with the General University Hospital of Prague and the newly established Czech patient organisation [Vaskulitida.cz](https://vaskulitida.cz).

- **Participants:** 60 patient representatives, physicians, and specialist nurses
- **Countries represented:** 16

The programme focused on innovative therapies, emerging tools in vasculitis care, and long term quality of life. Equally important was the opportunity for participants to exchange experiences, strengthen cross-border collaboration, and build sustainable professional relationships.

A [detailed post-event report](#) is available on our website

Germany

German vasculitis self-help groups expressed a clear need for improved collaboration, both nationally and across German-speaking countries. To support this, Vasculitis International developed a dedicated German-language platform: [Vaskulitispatienten.de](https://vaskulitispatienten.de).

We continued efforts to establish closer cooperation with the German Rheuma Liga, recognising their central role in patient advocacy. While progress has been limited so far, these efforts will be intensified in 2026, with a continued emphasis on complementarity rather than competition.

Limited resources and language barriers remain challenges for German self-help groups. In 2025, patient representatives from France, Poland, and Finland—fluent in German, English, and their native languages—formed a project team to explore support mechanisms. One planned initiative for 2026 is a joint meeting for German self-help groups to enhance mutual collaboration.

Czech Republic

In 2025, Vasculitis International supported the establishment of the first formal vasculitis patient organisation in the Czech Republic. Support included:

- Development of a logo and visual identity
- Creation of a comprehensive website (vaskulitida.cz)
- Provision of banners and promotional materials

Hosting the European Vasculitis Patient Summit in Prague further increased visibility and provided the Czech organisation with valuable learning and networking opportunities.

Spain

The Spanish patient group faced significant organisational challenges due to health issues among board members and volunteers, which prevented participation in the Prague Summit. Through our network, we facilitated the participation of a Spanish physician and two patients. In collaboration with a leading professor in Barcelona, plans were initiated to support the strengthening of the Spanish group in 2026.

Italy

The Italian patient group **APACS** expressed the intention to establish a **European EGPA Patient Group**. During the Prague Summit, APACS presented this initiative and connected with EGPA representatives from several countries to explore next steps.

Ireland

During the summit in Prague the Irish organisation **VIA** presented its **chatbot Dwayne**, designed to support patients with vasculitis. This initiative sparked interest among other patient groups, opening opportunities for knowledge sharing and future collaboration on similar digital tools.

Developing Products and Services

Product and service development is a key strategic objective. The German-language platform and the Czech website are prime examples of products designed to strengthen national patient organisations. However, the development of these platforms—combined with the extensive efforts required to organise the 3rd European Vasculitis Patient Summit—fully utilised available volunteer capacity in 2025.

As a result, additional product development has been scheduled as a priority for 2026, including the creation of a shared resource library for member organisations.

Expand

New Members and Partnerships

In 2025, the Swiss organisation **VASAS** and the Vasculitis Foundation joined Vasculitis International. We strengthened ties with the European **EGPA Study Group (EESG)**, establishing reciprocal links between our organisations.

New Country Initiatives

Physicians from **Portugal** expressed interest in establishing a patient organisation; follow-up actions are planned for 2026.

The Takayasu patient group from **Spain** expressed an interest in joining and will do so in 2026. Representatives from **Sweden** and **Denmark** attended the Prague Summit. Interest was expressed—particularly from Lund—for the development of a Swedish-language vasculitis website. Needs assessments for Swedish and Danish platforms will be conducted in 2026.

Greece

After governance changes within the Greek organisation **ELEANA**, relations were successfully re-established. Board members attended the Prague Summit, and closer collaboration is planned.

Strengthen the Internal Organisation

Vasculitis International operates with a limited but highly committed group of volunteers. In 2025, the Board focused on ensuring that organisational growth and external activities remained aligned with available capacity, governance standards, and long-term sustainability.

Key governance principles guiding our work included:

- **Strategic alignment:** All major activities were assessed against the Strategic Plan 2025–2027 to ensure relevance and focus.
- **Responsible stewardship:** Financial and human resources were allocated prudently, prioritising activities with clear European added value.
- **Transparency and accountability:** Decisions regarding partnerships, events, and platform development were documented and discussed within both the legal and operational Board.
- **Risk awareness:** Particular attention was paid to volunteer workload, organisational continuity, and reputational integrity when entering new collaborations.

While the organisation successfully delivered major initiatives, the Board recognises that these activities fully utilised available capacity. This informed the decision to prioritise consolidation, product development, and internal strengthening in 2026.

The organisation's website, which has served effectively during the first five years of operation, was formally assessed in 2025. The Board concluded that a comprehensive renewal is required to meet current standards for professional presentation, accessibility, and technical resilience. Preparatory steps for this renewal will be taken in 2026.

Key Outcomes and Impact 2025

Strategic Impact

In 2025, Vasculitis International delivered measurable strategic impact across Europe by strengthening patient representation, improving access to knowledge, and fostering sustainable collaboration between patient groups and medical professionals.

- **European reach strengthened:** Active engagement with patient organisations and healthcare professionals from 16 European countries.
- **Capacity building:** Support provided to both emerging and established patient organisations, enabling them to professionalise governance, communication, and advocacy.
- **Medical–patient collaboration:** Stronger integration of patient perspectives into discussions on care pathways, nursing specialisation, and innovative therapies.

Organisational Outcomes

- **3rd European Vasculitis Patient Summit** successfully delivered, now established as a recurring and recognised European platform.
- **New national organisations** supported or initiated, most notably in the Czech Republic.
- **Multilingual digital infrastructure** developed, including German- and Czech-language platforms, significantly improving accessibility for patients.
- **Network expansion**, with new member organisations and reinforced partnerships with European medical study groups.

Value for Funders and Partners

Despite operating with a lean, volunteer-driven structure, Vasculitis International demonstrated a high return on investment by:

- **Translating limited financial and human resources into Europe-wide impact**
- **Avoiding duplication of efforts through cross-border collaboration**
- **Creating reusable tools and platforms that benefit multiple countries**

These outcomes position Vasculitis International as a reliable, efficient, and strategically focused partner for funders committed to improving outcomes for people living with rare and complex diseases.

Conclusion

The year 2025 can be characterised as a milestone year in which Vasculitis International became firmly anchored within both the patient and medical communities. The European Vasculitis Patient Summit has now been established as a recognised, high-quality meeting that delivers meaningful content and fosters collaboration.

We remain fully committed to serving the vasculitis patient community and will continue to build on these foundations in the years ahead.

Maarsse-NL, January 2026

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