

Vascern missions

Created in 2017, the European Reference Network on Rare Multisystemic Vascular Diseases (VASCERN) gathers highly specialized expert Healthcare Providers and their multidisciplinary teams, together with patients and the scientific community, to tackle the challenges faced by patients, their families, and clinicians in this area of expertise.

VASCERN's general goals are to:

- Increase the knowledge of clinicians and patients thanks to training and education online activities.
- Improve medical knowledge by sharing experience, conducting clinical trials and creating registries.
- Reduce the delay in diagnosing the diseases.
- Improve awareness for the diseases among stakeholders, general practitioners, school doctors, general public.
- Improve the quality of family counselling and reduce care gaps.

The Patient advocate

The VASCERN European Patient Advocacy Group (ePAG) is comprised of patient advocates that represent and are endorsed by a patient organisation following the process described in Sections 13-14.

The overarching objective of the ePAG is to ensure that the needs of people living with rare and complex conditions covered by the ERN are included in its strategic and operational delivery.

To achieve this goal, the ePAG role is to:

- Represent the voice and interests of patients and carers within VASCERN.
- Ensure a patient-centric approach in the collaborative activities of VASCERN in the areas of care, education and training, knowledge sharing and research.
- Support the identification of VASCERN strategic priorities.
- Provide input on ethical issues.
- Support the Network in the dissemination of its activities and information to the wider patient community to ensure transparency.

Role of VASCERN ePAG advocates

ePAG advocates are patient representatives that are active in the ERN www.vascern.eu including the Network board and council and working groups.

The ePAG advocates role is to:

- Work in partnership with other patient advocates, clinicians and researchers involved in VASCERN.
- Champion the diversity of views of the VASCERN patient community, and not just to represent their own disease area nor their own experience.
- Support VASCERN to disseminate information, primarily to the patient community, but as appropriate to other communities (e.g., healthcare providers, health authorities, clinicians and medical professionals and their professional bodies)
- Contribute to the development of patient information, clinical practice guidelines, other clinical decision support tools and referral pathways.
- Contribute to the development of research priorities and ensure the needs of patients and families are taken into consideration.
- Provide input on ethical issues, and balance patient and clinical needs appropriately.
- Scout for other patient organisations in underrepresented countries per disease.

Responsibilities of VASCERN ePAG advocates

All ePAG advocates will be required to:

- Participate in VASCERN working groups (depending on interests, expertise, and availability).
- Participate actively and promptly when and how required by the ePAG co-chair and deputy co-chair and send apologies in advance if unable to attend.
- Report regularly in the ePAG calls and meetings on the progress of the work and projects in which they are directly involved in VASCERN. If unable to attend, the report should be sent by email ahead of the meeting or call.
- Participate in VASCERN annual meetings, where possible. VASCERN policy allows the participation of 3 ePAG advocates per disease working group. The number could increase based on availability. The co-chair and deputy co-chair nominate the ePAGs to attend based on their specific involvement in ongoing projects and/or manifests motivation for additional involvement. Travel and accommodation expenses will be reimbursed subject to the ERN budgetary rules.
- Contribute to identify and develop the ePAG annual objectives and work programme.
- Contribute to the assessment of new applications for membership of the ePAG.
- Respect the confidential nature of the discussions when it is made clear that this is a requirement by the person who is chairing a call or meeting.
- Comply with the VASCERN conflict of interest policy.
- Adhere to the terms of the mediation agreement in the case of a mediation process described in the EURORDIS ePAG Constitution and Rules of Procedure.

All ePAG advocates also commit to adhering to the following set of core values:

- Respecting the mission of the VASCERN and its governance structure.
- Listening to the opinions and requests of others.
- Showing solidarity, mutual respect, and support.
- Adhering to the principles of equity and social justice.
- Conducting themselves with professionalism in engaging with the clinical, research leads and fellow patient advocates.

Contact information

For more information about Vascern and the Pediatric Primary Lymphedema (PPL) working group, please contact

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