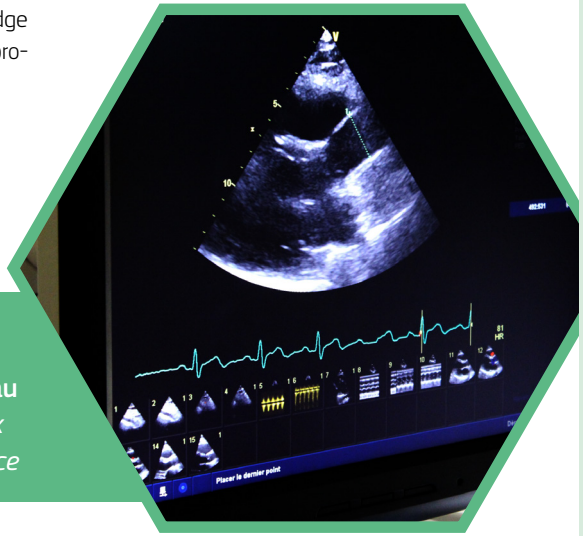
ERN on multisystemic vascular diseases (VASCERN)

Rare multisystemic vascular diseases include disorders which affect all types of blood vessels, with consequences for several body systems which require a multidisciplinary approach to care. VASCERN comprises six rare disease working groups on hereditary haemorrhagic telangiectasia (HHT-WG); heritable thoracic aortic diseases (HTAD-WG); medium sized arteries (vascular Ehlers Danlos Syndrome) (MSA-WG); paediatric and primary lymphedema (PPL-WG); vascular anomalies (VASCA-WG); and neurovascular diseases (NEUROVASC-WG). In addition, there are several thematic working groups which address communication, registries, ethics and issues related to pregnancy. A dedicated ePAG enables patient advocates to be involved in all VASCERN activities.

VASCERN's objectives include networking, sharing and spreading expertise; promoting best practices, guidelines and clinical outcomes; patient empowerment; and improving knowledge through clinical and basic research.

Healthcare professionals involved in VASCERN have already made educational materials, such as webinars and the 'Pills of Knowledge' series of videos, available online for both doctors and patients. The network has published consensus statements and clinical decision-making tools - including patient pathways, and 'Dos and Don'ts' factsheets - to provide advice on the proper diagnosis and care of patients with rare diseases. Digital eHealth services such as the VASCERN mobile app have been developed in collaboration with all the expert centres and patient organisations of the ePAG. Exchanges between member institutions are being set up, and the network continues to share knowledge both with members and with healthcare professionals outside the ERN.



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