VASCERN HTAD registry

CleanWeb[™] (tentelemed.com)

What is CleanWeb?

VASCERN HTAD registry is using CleanWeb and is a European-wide registry set up by VASCERN in which patient data can be collected for research purposes.

The goal of the registry is to improve research in rare vascular diseases by increasing patient numbers and make data more accessible and reusable (FAIR-principle).

Where is the information stored?

The data is stored and controlled locally at the Assistance-Publique Hôpitaux de Paris (3, Avenue Victoria, 75004 Paris, France)

If you have any questions or inquiries, please follow the instruction below

For Patients:

- For questions regarding your participation or data, please consult your treating physician.
- For inquiries regarding data security, kindly email vascern registry@vascern.eu.

For Researchers or Policymakers:

• If you are a researcher or policymaker seeking information related to data utilization, please reach out to <u>dac@vascern.eu</u>.

For General Inquiries:

• For any other questions or concerns regarding the HTAD registry, please contact <u>htad registry info@vascern.eu</u>.

Data elements:

All elements collected in this registry can be found <u>here</u>.

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