



Endo-ERN

# Endo-ERN short

- 86 Centres in 27 countries
- 16 ePAGs (Denmark, UK, Germany, France, Netherlands, Italy)
- 8 Main Thematic Groups en 5 Work Packages
- Steering Committee for every MTG and WP: Adult and Paediatric Endocrinologist and an ePAG



- MTG1 Adrenal
- MTG2 Disorders of Calcium & Phosphate Homeostasis
- MTG3 Genetic Disorders of Glucose & Insulin Homeostasis
- MTG4 Genetic Endocrine Tumour Syndromes
- MTG5 Growth & Genetic Obesity Syndromes
- MTG6 Pituitary
- MTG7 Sex Development & Maturation
- MTG8 Thyroid

- WP1 Education & Training
- WP2 E-Health & ICT
- WP3 Research & Science
- WP4 Quality of Care & Patient View
- WP5 Diagnostics & Laboratory Analysis



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**VSOP** 

- The VSOP (Dutch rare disease National Alliance) is closely engaged with the ministry of Health (VWS), The Federation of University Hospitals (NFU) and patients organisations for rare conditions and they fulfil a fundamental role in the assignment process of centers of expertise and the national plan for rare diseases (NPZZ); next round is expected around the summer.
- Rate of engagement of ePAGs differs enormously; Ranging from established ePAGs and patients who like to learn more on ERNs; some ePAGs never met coordinators and/or chairs or even HCPs from the network
- National Alliance is not fully aware of the work of ERNs; Assumes that every ERNs is organized identically and that creates some misunderstandings and wrong assumptions (e.g. definition of Work Packages)



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**VSOP** 

- Meetings funded on budget provided by ministry of Health; max. 3 meetings in total; after that nothing else will be organised, unless additional funds are provided
- A large meeting with ERN coordinators, ePAGs, University Federation and Ministry of Health will be organized (now postponed due to Covid-19, maybe in June either face 2 face or online)
- Before integrating ERNs in National Networks there still a lot of work to be done: peripheral centers not always are efficiently connected to centers of expertise and also within some ERNs centres of expertise do not always work together effectively and efficiently on a national level, but there are other examples:
- Recent collaboration with the VSOP: Project Connect Extended (Caroline van den Bosch from HEVAS and ePAG Advocate of VASCERN)

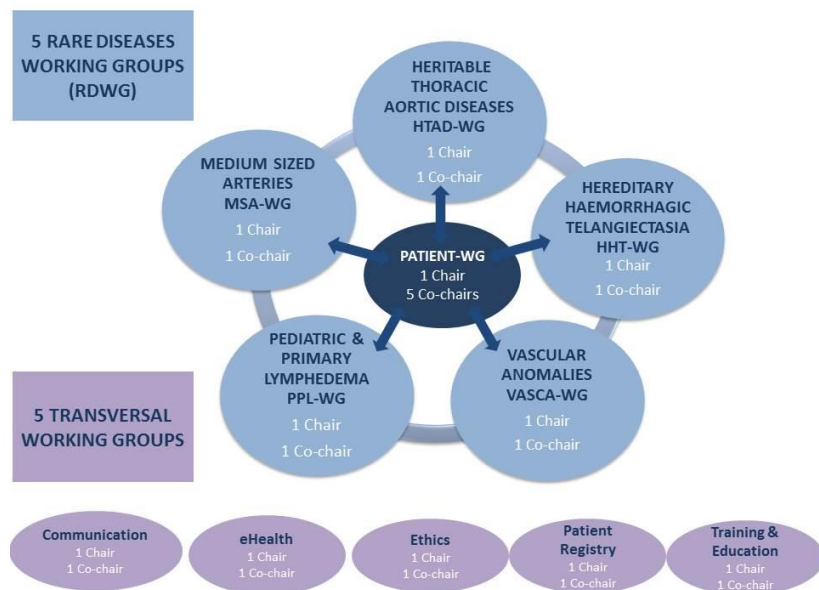


# VASCERN and the Patient Workgroup

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**ERN Rare multisystemic vascular diseases (vascern.eu)**

**VASCERN PATIENT WORKGROUP**



## VASCERN EUROPEAN PATIENT ADVOCACY GROUP (ePAG)



## Initial situation

- ❑ 10 years ago, beginning of collaboration between Hevas and 4 Dutch Centers of expertise on Vascular Anomalies.
- ❑ One of the 4 Dutch Centers is Full Member of the VASCA Working group within VASCERN.
- ❑ Regular face to face meetings and conference calls.
- ❑ Initiating a national network of centres of expertise at national level.

## Project Connect Extended

- ❑ In 2019, Hevas joined the Pilot Project Connect Extended driven by the Dutch Patient Alliance for Rare and Genetic Diseases (VSOP).
- ❑ 26 centres of expertise, 11 patient organisations and 16 rare diseases represented.
- ❑ Creation of a common website of centers of expertise.
- ❑ Collaboration between centers of expertise, patients and care providers.
- ❑ Interaction in the field of care and research.
- ❑ Creation of National networks of Centers of Expertise.

## Common platform

**IBM EXPERTISECENTRUM**

Het expertisecentrum Voor patiënten Voor zorgverleners Research

Home » Het expertisecentrum IBM



### Het expertisecentrum IBM


In Nederland zijn de universitaire medische centra verbonden via Spierziekten Centrum Nederland. Hierdoor wordt kennis over spierziekten gedeeld zodat u als patiënt voor een goede diagnose of behandeling terecht kan in elk academisch ziekenhuis. Het Amsterdam UMC, het Radboudumc te Nijmegen en het LUMC te Leiden bundelen hun krachten op het gebied van onderzoek naar IBM en vormen daarmee het IBM expertisecentrum.

[Meer informatie →](#)

### Uw bezoek aan het expertisecentrum

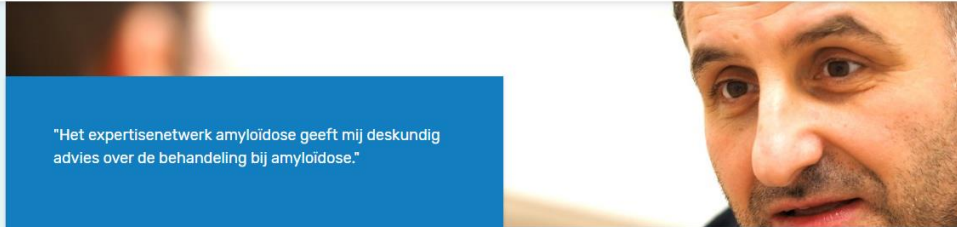
Voor uw eerste bezoek aan het expertisecentrum heeft u een verwijzing nodig van uw huisarts of neuroloog. U kunt ervoor kiezen regelmatig terug te komen voor controles. Bekijk onze video.

[Lees meer over uw bezoek →](#)



**AMYLOIDOSE EXPERTISENETWERK**

Het expertisenetwerk Voor patiënten Voor zorgverleners Research



"Het expertisenetwerk amyloidose geeft mij deskundig advies over de behandeling bij amyloidose."

[Lees meer →](#)

UMCG

Zoek op trefwoord, bijv. vermoeidheid.... [Zoeken →](#)

[Veelgestelde vragen patiënten](#)

[Veelgestelde vragen zorgverleners](#)

### Het expertisenetwerk

Voor uw eerste bezoek aan het expertisenetwerk amyloidose heeft u een verwijzing nodig van uw huisarts of specialist. Het expertisenetwerk amyloidose beoordeelt waar uw behandeling het beste kan plaatsvinden. Bekijk onze video.

[Lees meer →](#)





### Contribution to patient engagement and improvement of care

- ❑ Strong visibility and legitimacy of the participating healthcare centers in a recognized national network.
- ❑ Enhance cooperation between patient organisations and centers of expertise but also between the centers themselves.
- ❑ Easy access to understandable information for patients and their families.



## Success factors and lessons learned

- ❑ The Project Connect Extended is a good instrument to enhance a successful collaboration between the participating centers.
- ❑ Shared information on patients, treatments and care.
- ❑ Collaboration in sensitive topics (research and clinical trials).
- ❑ Patient organization at the center of the initiative.
- ❑ Possible scaling-up for other disease groupings but limited financial resources.



Thank you!

