



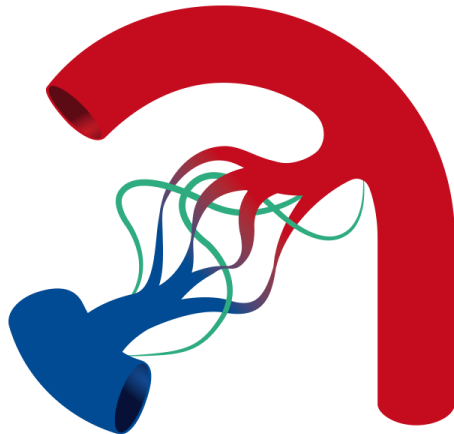
**European
Reference
Network**

for rare or low prevalence
complex diseases



Network

Vascular Diseases
(VASCERN)



WELCOME TO ONLINE

VASCERN DAYS 2020
22, 23, 24 October

Held on Whova


https://whova.com/portal/webapp/vasce_202010/

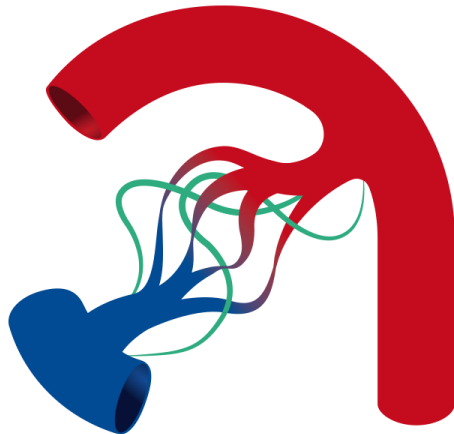
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8.45-12.05 VASCERN ANNUAL BOARD MEETING

8.45-9.00 Online connection to Whova and live stream
videoconference call

9.00-9.20

VASCERN's Management & Coordination
(Marine Hurard, Natasha Barr, Guillaume Jondeau)

- Welcoming words
- VASCERN's EU co-funding projects
- Monitoring, including meeting participation
- Mobile App Version 2
- Communication and dissemination

 **#VASCERNdays2020**



Welcoming words

Were invited

- **30 HCP full member (35 teams)**
 - from 11 countries:
 - 76 Healthcare professionals
- **7 HCP Affiliated Partners**
 - from 6 other EU Member States :
 - 12 Healthcare professionals
- **22 Patient Advocates**, members of our European Patient Advocacy Group



Welcoming words

Coordination & Project Management Team



Prof. Guillaume JONDEAU
VASCERN Coordinator
Cardiologist
Tel : +33 6 10 67 84 42
Email: guillaume.jondeau@aphp.fr



Marine HURARD
VASCERN Project Manager
Tel: +33 (0)1 40 25 80 66
Email: marine.hurard@aphp.fr



Natasha BARR
VASCERN Project Officer
Tel: +33 (0)1 40 25 70 76
Email: natasha.barr@aphp.fr



Karen DAOUD
VASCERN Project Assistant
Tel: +33 (0)1 40 25 70 77
Email: vascern.coordination@aphp.fr



Ibrahim DONMEZ
VASCERN IT Helpdesk & End-User
Support Specialist
Tel: +33 (0)1 40 25 67 22
Email: ibrahim.donmez@aphp.fr

Working in cooperation with AP-HP departments & the Foundation of the AP-HP
European Unit, Clinical Research Unit for registry projects, HR, IT, Finance, Buying, Communication, etc.

Welcoming words

- **Guests** from several institutions



DIRECTION
GÉNÉRALE
DE L'OFFRE
DE SOINS





General overview (morning sessions)

- Where we are :
 - Funding
 - Actions
 - Monitoring
 - Mobile App
 - CPMS
 - Each RDWG achievements
 - Enlargement
 - New HCPs
 - New pregnancy group
 - Registries
 - Opportunities from EJPRD (research)
- Topics of the year (s)
 - Outside ERN: National networks
 - Increasing recognition
 - New HCPs
 - Inside ERN:
 - Registries
 - Webinars
 - Others ? Brainstorming session



Agenda

Thursday Morning

- Plenary: Board session, including policy and project updates
- Feedback from RDWGs on Work Packages Implementation

Thursday Afternoon

- RDWG
- Council short wrap up on brainstorming topic selection

Friday, Morning

- EJP RD
- Registry WG
- Brainstorming
- Pregnancy WG 1st meeting

Friday, Afternoon

- RDWG
- Summary outcomes by RDWGs in plenary

Saturday, Morning

- RDWG (PPL, VASCA)
- ePAG separate wrap-up

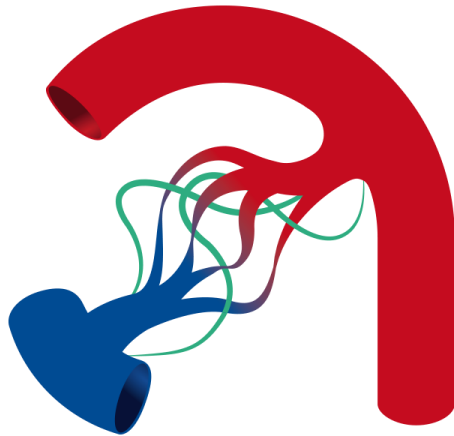


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VASCERN's EU co-funding projects

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3rd EU Health Programme: since March 2017

Current: 3 Years Specific Grant Agreement

March 2019-February 2022

ERN Management & Coordination:

Project Team (*manager, officer, assistant*), Meetings (*travel, hotel, rooms*), Communication (*webmaster, translations, scientific journal publications, app, etc.*)

600k EU co-funding (60% of budget)

400k co-funding France APHP & Health ministry (40%)



Co-funded by
the Health Programme
of the European Union

Connecting Europe Facility Telecom – eHealth for ERNs

since January 2019

Current: Grant Agreement 2020-March 2021

Next (Y3, deadline call 5/11): April 2021-September 2022

ERN eHealth Services

**CPMS & IT helpdesk, 1 Data Steward, Mobile App v2,
eLearning: PoK videos, Webinars, Monitoring: data
collection & validation, work on databases**

210k EU co-funding (75% of budget)

70k co-funding (25%) partners APHP & RadboudUMC



Co-financed by the Connecting Europe
Facility of the European Union

**VASCERN's multi-EU's
co-Funding**

3rd EU Health Programme NEW:

Registry Grant Agreement May 2020-May 2023

**5 registries project (*data stewards, licences, server hosting,
developers work on FAIRification*)**

200k EU Co-funding (60% of budget)

130k co-funding partners: APHP, RadboudUMC, INSERM, HCL



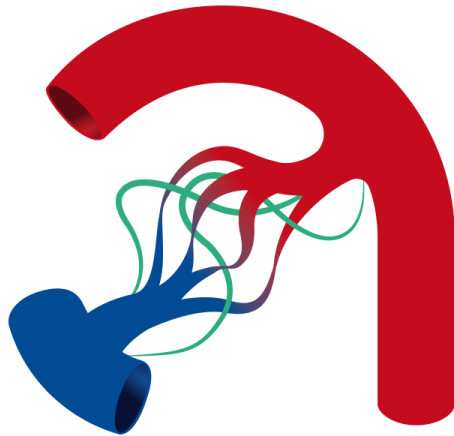
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**Monitoring, including
meeting participation**

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Internal: participation of HCPs & Affiliated Partners to meetings

HCPs Full Members & Affiliated Partners participation to monthly meetings is monitored for all VASCERN meetings

March 2019-August 2020

Total Board/Assembly:1 (Annual seminar, 2 day meeting)

Total Council:3

Total WG meetings:107 (*an average of 6 WG meetings/month: the 5 RDWG and the ePAG*)

Participation rate in 2019, including HCP Full Members and Affiliated Partners

VASCERN: 76%

HHT : 91%

HTAD : 76%

MSA : 69%

PPL : 71%

VASCA : 75%

VASCERN Authorship Guidelines (important for monitoring by EU)



- All publication in affiliation : "VASCERN HTAD European Reference Centre"

- 2 or more VASCERN centers from 2 more more countries are authors:

in acknowledgements

"This work is supported by the European Reference Network on Rare Multisystemic Vascular Diseases (VASCERN) - Project ID: 769036 partly co-funded by the European Union Third Health Programme"

Funding:

-direct : article-processing charges

-indirect : meetings where discussed, communication, etc.



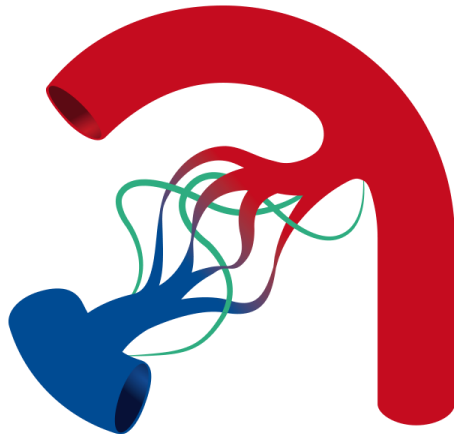
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VASCERN's Terms of Reference addition

 [#VASCERNdays2020](https://twitter.com/VASCERNdays2020)

Confidentiality Rules on the Collaborative Platform (ECP) & other platforms used (dropbox, emails...)




- **Only final documents** can be shared outside of the network,
 - Usually available on the website.
 - External share only if external expertise needed : patients associations, external experts.
- **No patient identifying data** in any form should be shared
 - The sharing of data and the protection of patient information is subject to the EU legislation on the protection of personal data (Directive 95/46/EC and General Data Protection Regulation) and to national legislation on data protection

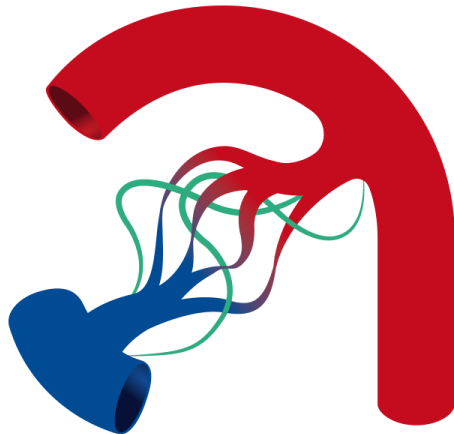
The coordination team has the right to delete any documents that do not respect patient confidentiality rules.



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Mobile App

Version 2

<https://vascern.eu/what-we-do/mobile-app/>

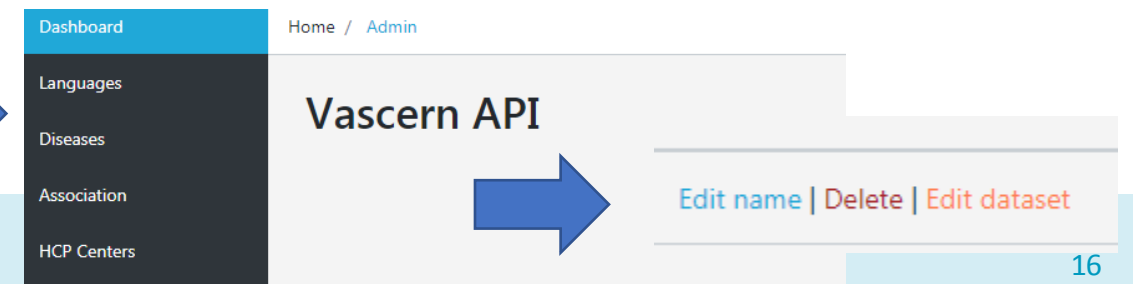
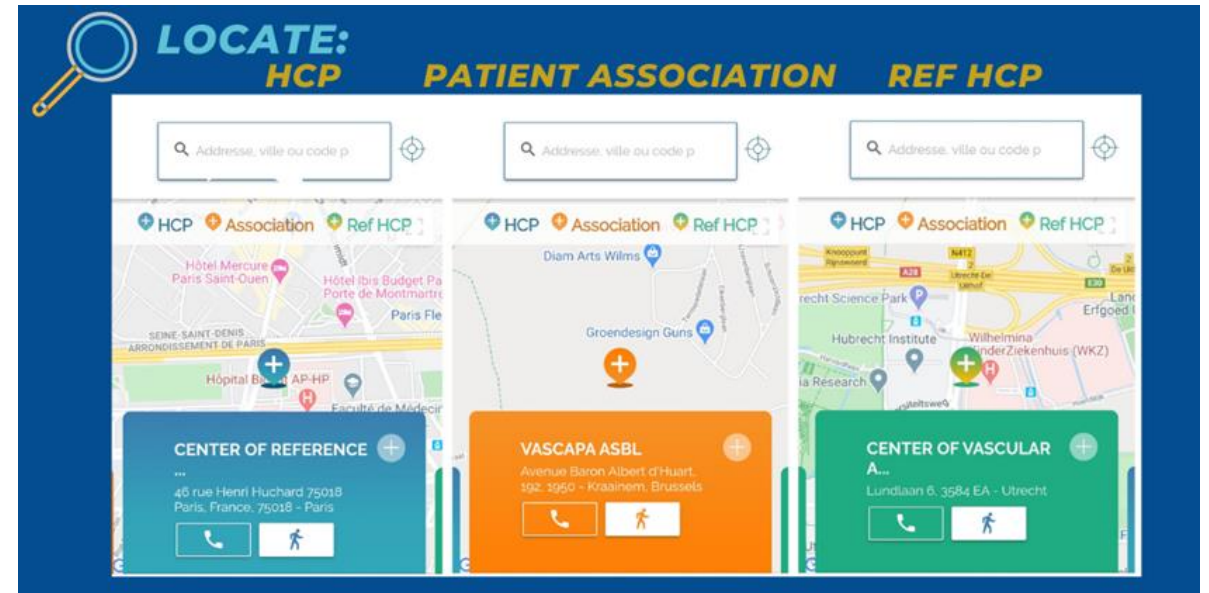
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VASCERN App 2.1 _ launched August 2020

Version 2.1: Improvements implemented

- **Multilanguage:** menu / structure and diseases are translated
- **Cards editing:** only in English by default in all languages version of the mobile app, to remain accessible for all everywhere
- **35 European Reference Centers** in our 30 Full HCP Members + **7 Affiliated Partners**
- **66 Patient Organisations**, and working with the ePAG Co-Chairs towards including all the patient organisations members of the ePAG community
- **33 Referral HCPs** from France (22), The Netherlands (5), Belgium (3), Italy (2), UK (1). **Need HCPs to send dataset from their national networks!**
- **Easy update:** each user has access to its own data for updating: <https://vascern.azurewebsites.net/>
- **Backoffice and App management & requests:** VASCERN's Project & Coordination Team in Paris





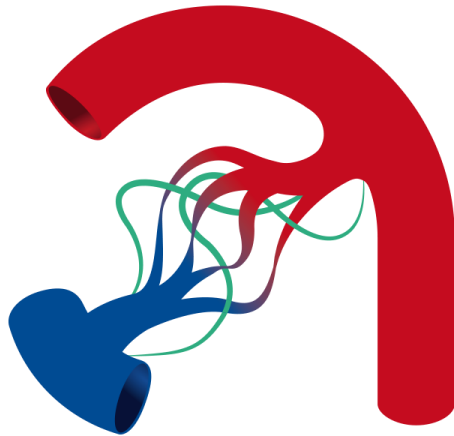
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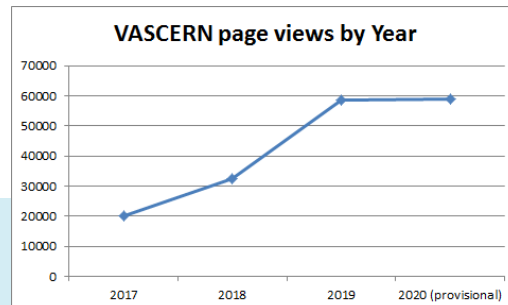
Communication and dissemination

 [#VASCERNdays2020](https://twitter.com/VASCERNdays2020)



New this year:

- VASCERN's COVID19 recommendations button
- Updates to the content and structure of many of our pages (RDWG, Transversal WG, ePAG, CPMS)
- New ePAG advocates (all in VASCERN mobile app also on website), 7 New affiliated Partners, New Registries Project Team all added



Website hits

Total page views (hits) in 2017: 20,312
 Total page views in 2018: 32,509
 Total page views in 2019: **58404**
 Total page views in 2020 (to date): 41607

Same 11 sections on each RDWG page for consistency and for easier validation of EC's monitoring indicators.



- ✓ Presentation
- ✓ Heritable Thoracic Aortic Diseases (HTAD-WG)
- ✓ Healthcare Provider Full Members, Affiliated Partners & ePAG Co-Chairs
- ✓ Webinars and Pills of Knowledge Videos (Educational Videos)
- ✓ Patient Pathways (Clinical Decision Support Tools)
- ✓ Clinical Practice Guidelines (CPGs) adopted
- ✓ Clinical Expert Consensus Statements Written (Clinical Decision Support Tools)
- ✓ Do's and Don'ts Factsheets (Clinical Decision Support Tools)
- ✓ Outcome Measures
- ✓ Registry
- ✓ Collaborative Research and Publications

That correspond with the sections of "what we do"



VASCERN Social Media channels




2019

2020



#VASCERNDays2020

675 →  886 Followers

<https://twitter.com/vascern>

518 →  Total Page likes: 682

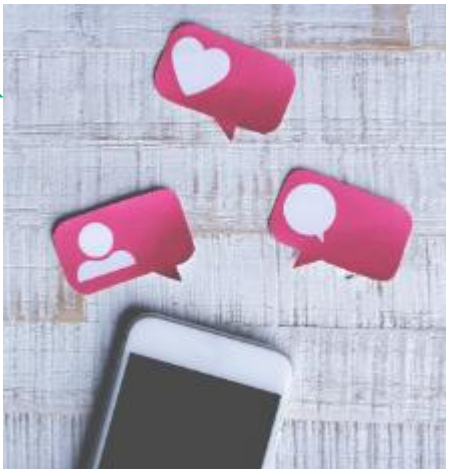
<https://www.facebook.com/vascern.eu/>

181 →   VASCERN ERN Rare Vascular Diseases
505 abonnés
<http://www.youtube.com/c/VASCERNERNRareVascularDiseases>

156 →  266 Total followers
<https://www.linkedin.com/company/vascern/>

 Patient-focused VASCERN Instagram account
→ our legal entity, APHP refusal (patient data)

Abonnés
+326
↑ 163 %



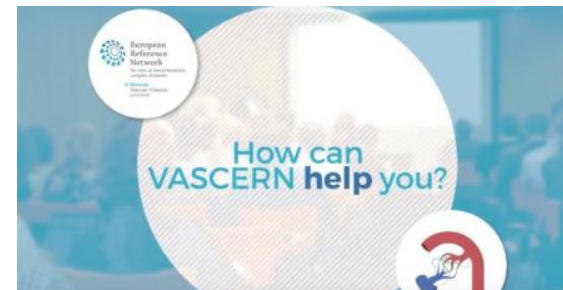
Continued increase of followers and engagement on all our social media channels



How can we increase VASCERN's outreach!



- Present VASCERN at conferences
- acknowledge VASCERN in scientific publications
- Share our news/outputs on social media
- VASCERN link on your website
- Endorsement of events by VASCERN



« [How can VASCERN Help You?](#) » Video: 2251 views to date (since January 2019)!

Subtitles available in all EU languages
Please share

Example of collaboration this year:
E3 International Summit with the
Marfan Foundation! 2 810 registrants
from 75 countries

[Subscribe to our newsletter!](#) 379 subscribers: let's increase!

→ [Flyer](#)

→ [Web version here](#)

→ [Print version here](#)

