




European
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Network

for rare or low prevalence
complex diseases

 **Network**
Vascular Diseases
(VASCERN)

8.30-12.15: PLENARY SESSION

8.30-9.00: **Welcome by Prof Guillaume Jondeau and brief introduction by all participants (30')**

9.00-9.45: VASCERN Structure & Organisation: State of play 1 (45')

Presentation of VASCERN & Functioning since March (20') (Guillaume Jondeau, Marine Hurard)
Feedback, Q&A and discussion (25')

9.45-10.05: **VASCERN Patient Group (ePAG) (20')** including Q&A

ePAG involvement within VASCERN, co-presentation by the Patient Group Chair & EURORDIS (Paolo Federici, Matt Bolz-Johnson)

Q&A

10.05: coffee break

Photo booth

10.20-11:20: **VASCERN 1st year Action Plan: State of play 2 (60')**

Objectives & state of play of Work packages (Marine Hurard) & Feedback from the Council (Guillaume Jondeau and WGs Chairs: Julie de Backer, Claire Shovlin, Leema Robert, Miikka Vikkula, Sahar Mansour, Alessandro Pini, Leo Schultze Kool, Paolo Federici) (40')

Q&A and discussion (20')

11.20-12.15: **Achievements, Challenges & Opportunities for ERNs (55')**

The ERN Policy (Anna Carta, ERN Team, DG SANTE, European Commission) (10')

The ERN Collaborative platform and the Clinical Patient Management System (Jean-Marie Misztela)(10')

ERN Board of Member States views (Muriel Eliazewicz, French representative at the ERN Board of Member States) (10')


European Joint Programme on Rare Diseases Research: opportunities for ERNs (Daria Julkowska) (10')

Q&A (15')



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Medical view

Clinical Area of Expertise



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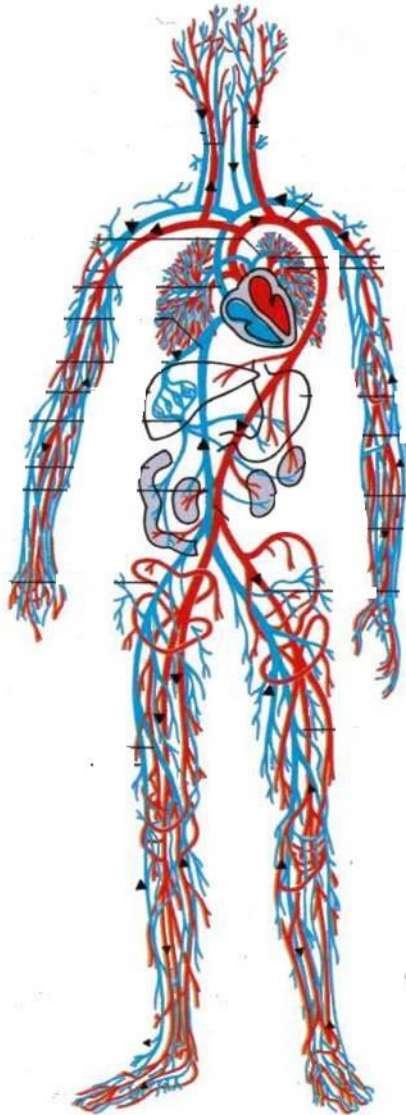
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Vascular Diseases

including rare, low prevalence and complex disorders that affect different types and sizes of vessels:

- Aorta **HTAD**
- Medium Size Arteries **MSA**
- Small Arteries / Veins / Lymphatics / Capillaries
 - **VASCA**
 - **HHT**
- Lymphedema **PPL**




and involving Multisystemic consequences and external signs (skeletal, dermatological, eyes, etc.)

1,3 million patients in the EU (*under-estimated prevalence*)



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Rare Diseases to be included in the Future


- **MSA-WG** (now including only vascular Ehlers-Danlos Syndrome):
 - Fibromuscular Dysplasia (FMD)





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Structural view

Healthcare Provider Members

Structure

Governance

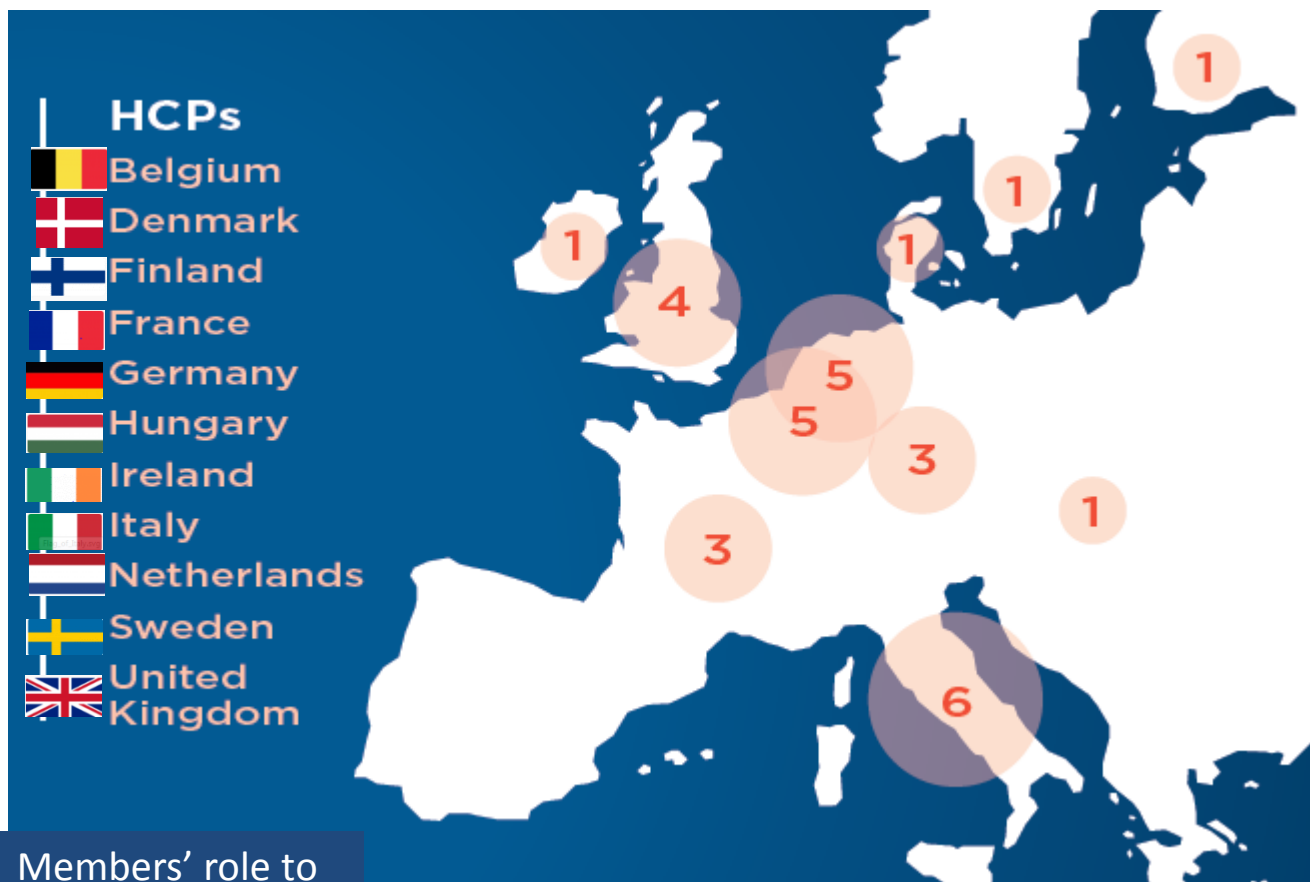


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31 HCP Members from 11 EU Member States



« **Affiliated Members**»: not yet developed, awaiting for Board of Member States designation

2018: new ERN Call for Membership, obj: extend to other EU Member States

Members' role to disseminate to their national networks



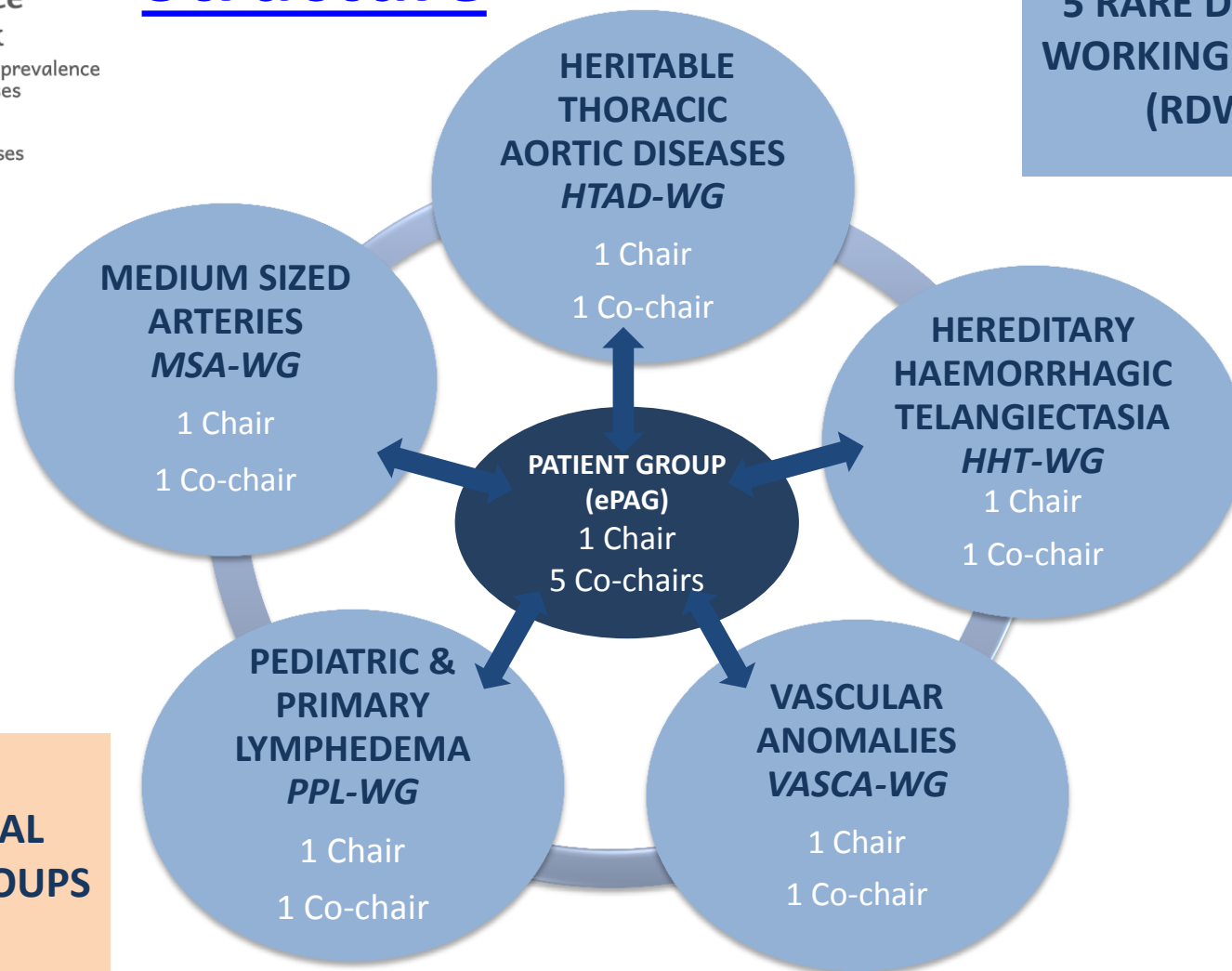
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Structure

5 RARE DISEASES WORKING GROUPS (RDWG)



TRANSVERSAL WORKING GROUPS

Patient Registry WG

1 Chair
1 Co-chair

eHealth

1 Chair
1 Co-chair

Training & Education

1 Chair
1 Co-chair

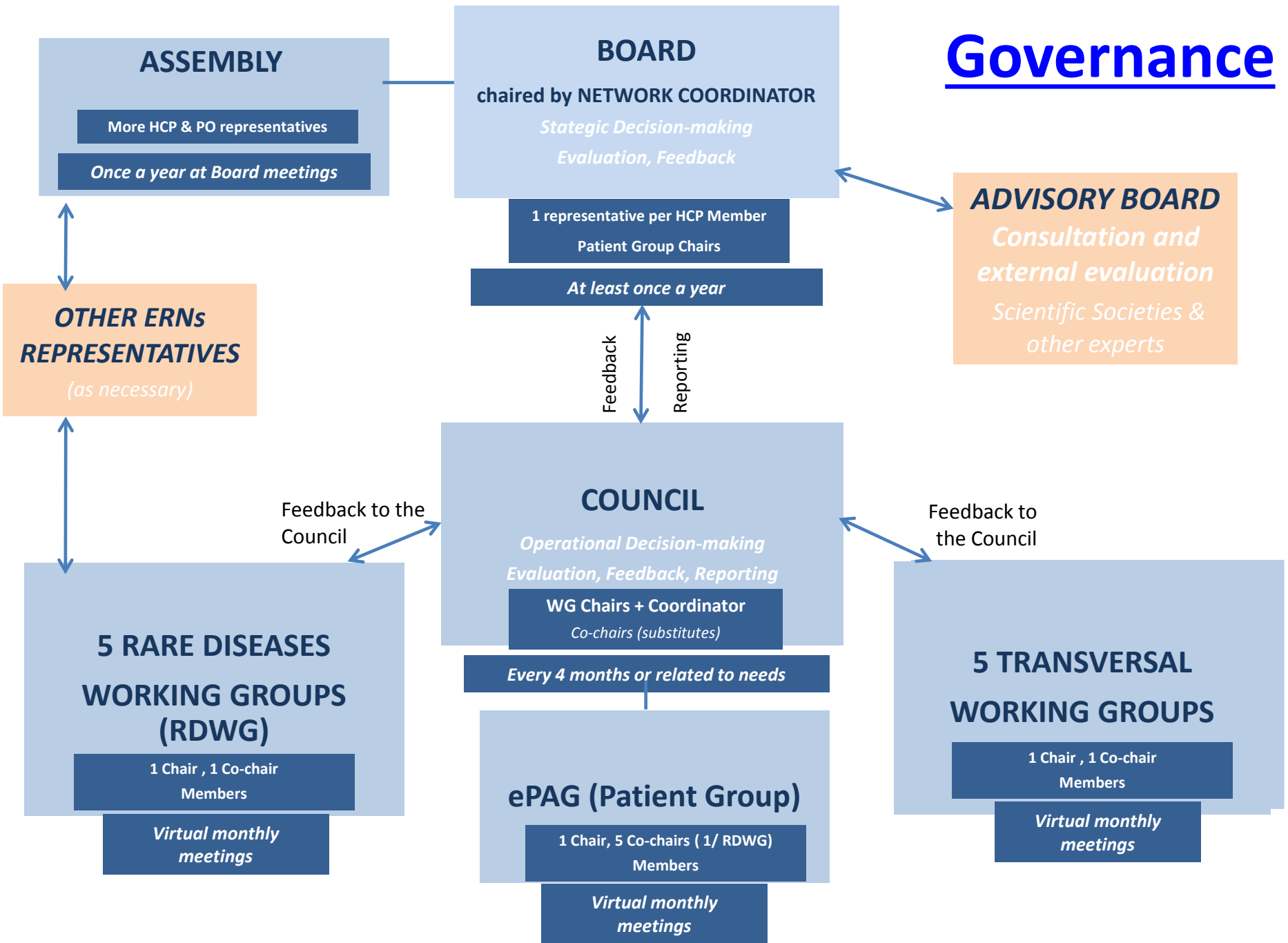
Ethics WG

1 Chair
1 Co-chair

Communication WG

1 Chair
1 Co-chair


Governance





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Inter-ERNs Working Groups

- **Medical:** ERN-Skin & further interERNs cooperation to be developed
- **Inter-ERN WGs:**
 - Monitoring, Assessment & Quality Improvement (Guillaume Jondeau)
 - Ethical & Legal issues (data protection, conflict of interest, informed consent)(Romain Alderweireldt)
 - Research (Xavier Jeunemaître)
 - IT & Data sharing
 - Knowledge generation: Training, education, capacity building, guidelines
 - Cross-border healthcare (organisation, provision)
 - Brexit



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What are our 1st year objectives?

10 Work Packages

(March 2017-February 2018)



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Action Plan March 2017-February 2018	
WP1	Sharing of experience: discussion of difficult clinical cases on a secured Clinical Patient Management System (CPMS) by each VASCERN Rare Disease Working Groups
WP2	Definition of patients pathways by each VASCERN Rare Disease Working Groups
WP3	Creation & Development of a cross-border pathways Mobile Application for IOS & Android
WP4	Pills of Knowledge
WP5	Registries: working towards the creation of a VASCERN registry - Survey of existing registries and biobanks - Minimum dataset
WP6	Clinical trials
WP7	Availability of conferences on YouTube
WP8	Definition of clinical outcomes
WP9	Writing recommendations J1: Clinical recommendations J2: Do's and Don'ts factsheets
WP10	Communication - Website - Social Networks - Monthly Newsletters - Collaborative Platform (internal communication) - Translation of material directed to patient care information



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How to reach the goals ?

The tools provided



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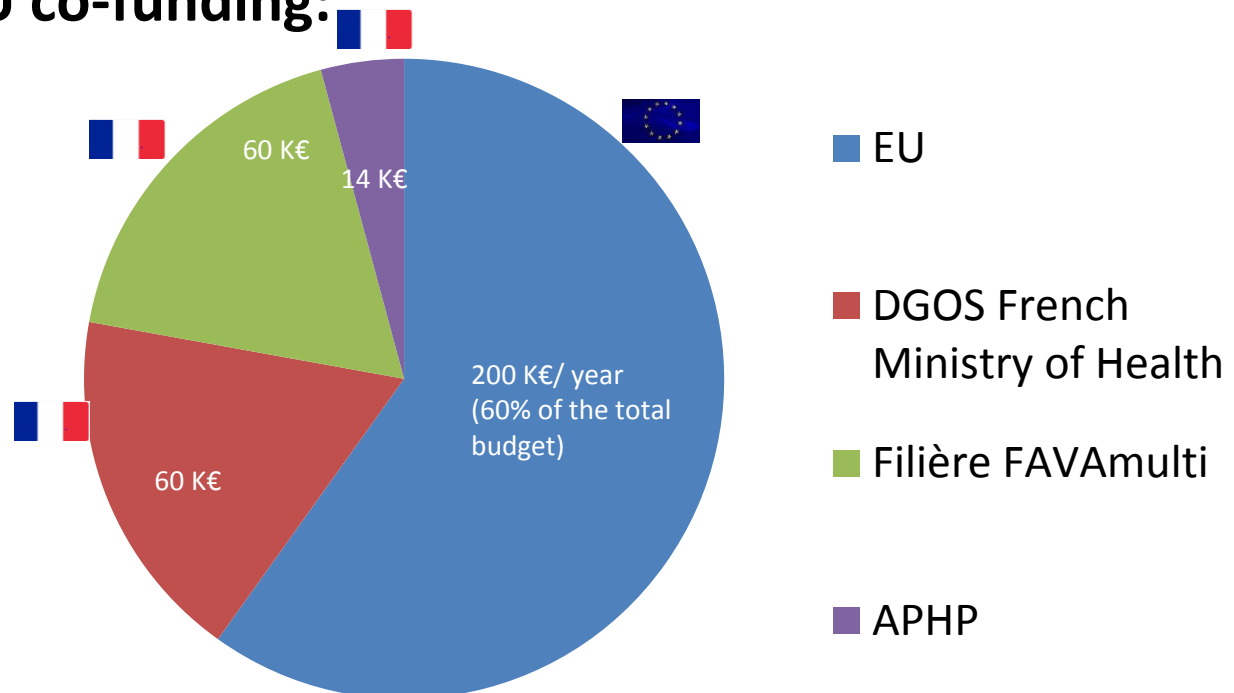
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Funding


- **Prior to EU co-funding:** Filière FAVA-Multi (funded by the DGOS, French Ministry of Health): European Development (2016, answer to ERN Call)
- **1st year EU co-funding:**





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Co-funded by
the Health Programme
of the European Union

- **EU co-funding for:**
 - Manpower: the VASCERN Coordination team
 - Meeting organisation
 - Communication, translation, eHealth tools
- **Virtual communication platforms:**
 - Videoconferences: Webex already used by all WGs
 - ERN Collaborative platform (ECP) for our Members (including documents storage, news, forums, shared agenda, library,...)
 - Clinical Patient Management System (CPMS): to be used soon
 - Ethics: informed consent



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« Medical knowledge and expertise that travel rather than the patients »

HOW WILL ERNS HELP PATIENTS?

Monthly RDWG videoconference meeting



Discussions on Work Packages & Clinical cases

The screenshot shows a Zoom meeting interface. The main window displays a PowerPoint slide titled "General Pathway" for HTAD (Hereditary Thoracic Aortic Disease). The slide content is as follows:

- Suspect of HTAD**
 - Family history:** Aortic Dissection, Aortic aneurysm, Skeletal features, Ectopia lentis, Recurrent pneumothorax
 - Personal history:** Aortic Dissection, Aortic aneurysm, Skeletal features, Ectopia lentis, Recurrent pneumothorax
- Genetic counseling**
 - Genetic testing (if appropriate)
 - Single genes? Panels?
- Multidisciplinary clinical evaluation**
 - Exclusion of other CRF: Cardiovascular imaging (Cardiac US - CT?), Ophthalmology, Skeletal evaluation, Pneumology
- Clinical diagnosis**
 - Morfan
 - LDS -> type
 - Non syndromic HTAD
 - Non H TAD
 - BAV-HTAD

The slide also includes the ERNS logo and the text "Network Vascular Diseases (VASCERN) VASCERN - HTAD WG".

On the right side of the Zoom window, the "Participants" list is visible, including:

- marine hurard (moi)
- Julie De Backer (Organisateur)
- alessandro pini
- Barbara Mulder
- Bart
- Call-in User_2
- Call-in User_3
- dulfer
- Erik Björck
- Gisela Teixeira Tura
- Guglielmina
- guillaume jondeau
- Ingrid van de Laar
- jolien
- Kalman Benke

Overlaid on the bottom right of the Zoom window is the text "HCPs & Patient Representatives".



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HHT WG Meeting #4, June 9th and 10th, Dubrovnik, Croatia

Posted 4 days ago by **Claire I. SHOVLIN** in the VASCERN network
Updated 4 days ago by **Kasper BEDSTED**

Members of the HHT WG met face to face to develop the WG Themes. The meetings were embedded in the 12th International HHT Scientific Conference in Dubrovnik, Croatia, where VASCERN presentations in (Shovlin on behalf of VASCERN HHT), poster (Buscarini on behalf of VASCERN HHT) and... [read more](#)



June 2017						
Mon	Tue	Wed	Thu	Fri	Sat	Sun
	5 10:00 ePAG virtual meeting 17:30 eHealth WG virtual meeting					
12 19:00 VASCA WG meeting		13 9:30 Ethics WG meeting				
19 17:30 PPL WG meeting						
26 17:00 HTAD-WG meeting		27 10:30 Council meeting 17:30 MSA-WG virtual meeting				
	3 10:00 ePAG virtual meeting					



optimizing difficult case discussions

Posted 2 months ago by **Leo SCHULTZE KOOL** in the VASCERN network in the Vascular Anomalies (VASCA-WG) forum

should we go for a specific format?
all submitted before the conference on powerpoint?

the questions are a bit of a test of this platform. just curious how many of the group read this. please respond

★ Remove like 2 ↔ More



Marine HURARD

Dear Leo,



Thank you for initiating this topic.

It would be good to have a specific format, standardized for case discussion within VASCERN. If you develop a draft for VASCA, we could duplicate for all RDWG?

Posted 2 weeks ago



Julie DE BACKER

I read your message Leo - thank you!



Although I think a template would be nice, I think that cases will be quite heterogeneous between (and even within) each WG.

Maybe a fixed template for the Title/First slide with the administrative data and a clear naming of the files that will be uploaded, so... [read more](#)

Posted 2 weeks ago



Claire I. SHOVLIN

Dear Leo, Marine and Julie



I am just learning how to negotiate this platform so our next WG Meeting can be without emails. In the HHT WG cases, we currently review a Word document with brief history sent around before the conference, then additions after the discussions, as Minutes. I am keen to template the final document with learning points but was planning to keep in Word. So maybe we could have a shell of how we have our layouts (eg logo, WG members, which I was about to do), and then could use to apply to Word, PPT or whatever. But I do not think it will be helpful to have an overly standardised format. As Julie says, cases are so heterogeneous. [read less](#)

Posted 4 days ago

write your comment here ...

Reply



ERN23 HTAD Mom 22/05/17

Posted 1 day ago by **Liesbeth WILDERO VAN WOUWE** in the VASCERN network

Minutes of WebEx-meeting

Resource Details

↓ ERN23 HTAD Mom 22/05/17 (0.00)

☆ Like 0

write your comment here ...



5 files have been uploaded in the folder "Minutes of Meeting"

Posted 1 day ago by **Miikka VIKKULA** in the VASCERN network

Resource Details

- ↓ VASCA minutes 20170214.pdf (0.00) ⓘ
- ↓ VASCA minutes 20170313.pdf (0.00) ⓘ
- ↓ VASCA minutes 20170410.pdf (0.00) ⓘ
- ↓ VASCA minutes 20170508.pdf (0.00) ⓘ
- ↓ VASCA minutes 20170612.pdf (0.00) ⓘ

- BOARD
- COUNCIL
- Patients-WG
- RDWG
 - HHT-WG
 - Agenda
 - Clinical outcomes
 - Guidelines
 - Minutes of Meeting
 - Patient pathways
 - Pills of knowledge
 - Presentations
 - Registry
 - Research/publications/clinical trials



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[IT Platform - Members area](#)

[HOME](#) [NEWS](#) [OUR NETWORK](#) [ERN](#) [EXPERTISE](#) [CLINICAL GUIDELINES](#) [CONTACT](#)

OUR VISION

"Our VASCERN project aims to facilitate and improve **diagnosis, treatment and care for ALL patients suffering from Rare Multisystemic Vascular Diseases**, thus enhancing access to care, and improving quantity and quality of life of these patients.

Networking, sharing and spreading our expertise, promoting best practices, guidelines and clinical outcomes, patient-empowerment, improving knowledge through clinical and basic research are among our objectives."

Prof. Guillaume Jondeau, Network Coordinator

Upcoming

MON
09
OCT
2017 **VASCA-WG monthly virtual meeting**
7 PM (Central European Summer Time)


TUE
10
OCT
2017 WED
11
OCT
2017 **ERN Coordinators Group (ECG) Meeting**

FRI SAT **VASCERN 1st Annual Seminar**



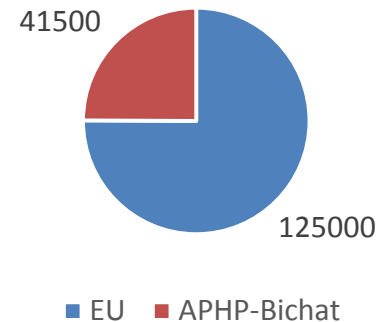
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CPMS Implementation

- **eHealth Call (CEF Telecom) for ERNs'** implementation of the **CPMS** (*Clinical Patient Management System*)
 - VASCERN proposal
 - Identical to all ERNs (*interERNs IT WG*)
 - to hire 2 IT staff: CPMS Operational Helpdesk
 - Submitted on September 21st, 2017
 - Evaluation expected by December 2017
 - Decision by Feb 2018. Grant by June 2018
 - 75% EU co-funding: 125000
 - 25% Co-funding APHP Bichat





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HOME NEWS OUR NETWORK ERN EXPERTISE CLINICAL GUIDELINES CONTACT

OUR VISION
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Prof. Guillaume Jondeau, Network Coordinator

All you need to know about ERNs

- ERNs Press Release
- ERNs Brochure
- ERNs Flyer

<http://vascern.eu/>

Communication & Dissemination



EUROPEAN REFERENCE NETWORK
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.



VASCERN @vascern
European Reference Network on Rare Multisystemic Vascular Diseases. Gathering the best expertise to improve care #EuropeanReferenceNetworks #RareDiseases
VASCERN.eu
Joined February 2017
44 Photos and videos

Tweets **Tweets & replies** **Media**

Pinned Tweet
VASCERN @vascern · Sep 28
Our 1st VASCERN 2 days annual Seminar (Paris, 13 & 14 October) is fast approaching! Follow us & tweet using #VASCERNdays2017 #ERNeu

VASCERN @vascern · 3h
Only 1 more week until #VASCERNdays2017 ! We're at the venue in #Paris today getting everything ready! #ERNeu

Who to follow · Refresh · View all

- Géant Casino** @geant_cas
- eni Communication** @eni...
- Flavio Minelli** @MinelliFla...

<https://twitter.com/vascern>

Follow us @vascern

Stay tuned!

- 29 JUN 2017
 - 29 JUN 2017
 - 01 JUL 2017
 - 22 SEP 2017
 - 23 SEP 2017
- Cardio Update Europe 2017
- ESVS 31th Annual Meeting 2017

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VASCERN Newsletter #8 - February 2017

View this email online

European Reference Networks Conference
The European Commission organizes the 3rd European Reference Networks Conference in Vilnius on March, 9-10th. This event will be the official launch and start of the first labeled European Reference...

EURORDIS 20th anniversary
2017 is EURORDIS-Rare Diseases Europe, the European association representing rare diseases, 20th anniversary. This is the opportunity to look at 20 years of achievements and challenges ahead here

3rd Health Programme WP 2017
The European Commission (DG Sanite) has adopted on January 26th the Work Programme 2017 under the 3rd Health Programme. This WP includes funding for supporting European Reference Networks (ERNs) with a total...

EU Call for Rare Disease Registries
The European Commission has published a Call for proposals for Projects on Rare Disease Registries for approved ERNs on December, 21st. EU CALL RARE DISEASES REGISTRIES (PJ-06-2016) Aim: increase knowledge.

HTAD-WG New Publication
A new HTAD-WG collaborative research paper has been published by Prof Guillaume Jondeau and GRM Martin team members (Dr Oliver Mikron, Maud Langeon, Myrtille Spertiniani, Prof Catherine Poirier) as well as HTAD-WG.

Upcoming

- 09 MAR 2017 - 10 MAR 2017: European Reference Networks Conference & ERNs Kick-off meetings
- 20 MAR 2017: Integrating Research and Healthcare for Rare Diseases: a structured cooperation with high community added value
- 21 MAR 2017: EU Call - Rare Disease Registries

Follow us on twitter

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VASCERN Get involved


EU Health @EU_Health
#EU supported ERNs will work to treat #rareDiseases affecting 5 in 10k people - around 30 million in the EU #ERNeu europe.eu/973kX

<http://vascern.eu/news/newletters/>



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What have we done ?

The meetings



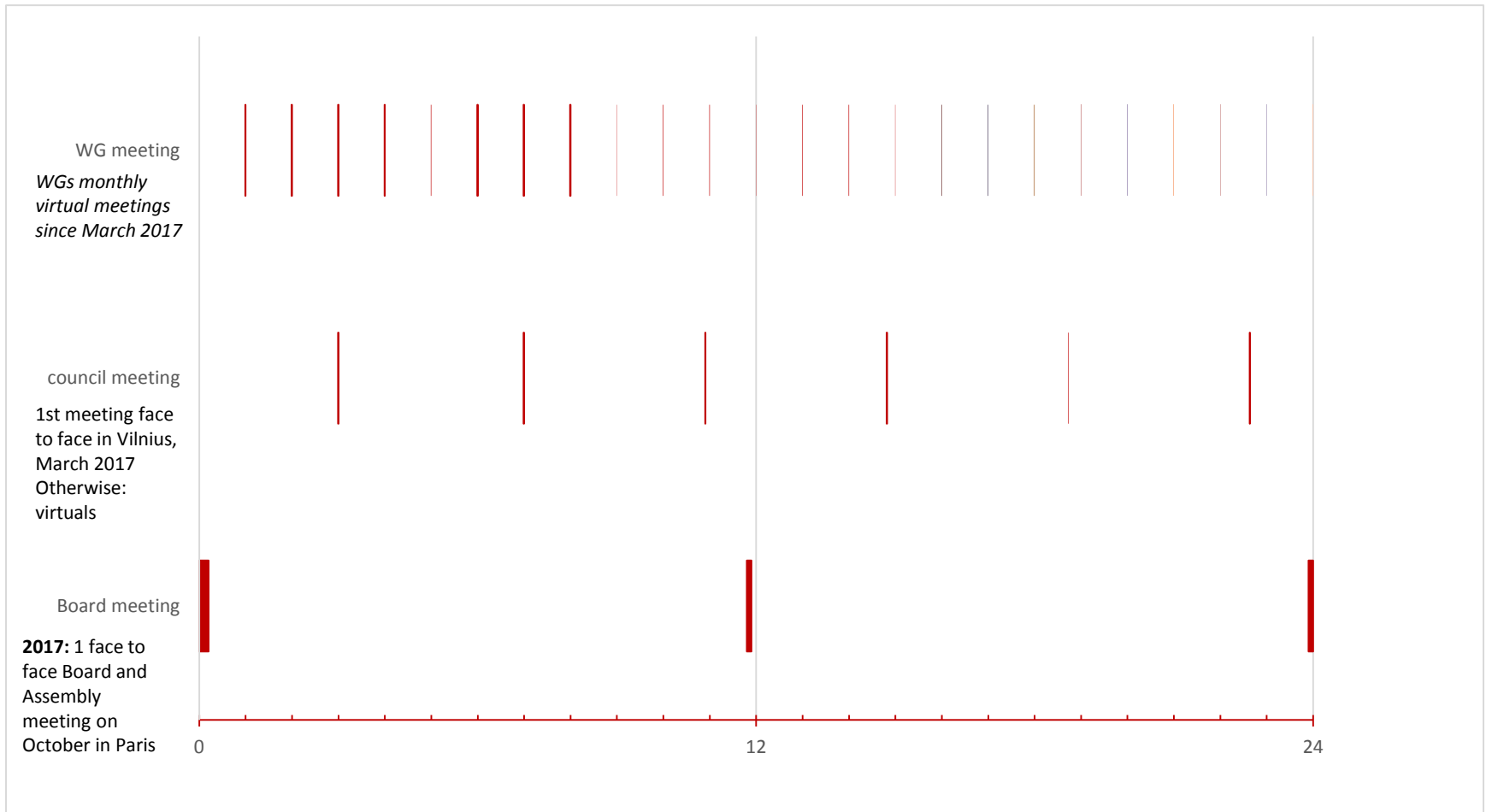
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HOW ARE WE WORKING?


Face-to-face & virtual videoconference meetings
Collaborative Platform & Website





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Meetings

- **Council:**
 - 1st in Vilnius, kick-off Council meeting, March 2017
 - 2nd virtual meeting, July 2017,
 - 3rd: follow-up of the VASCERN 1st Annual Seminar & Board meeting – before Dec 2017
- **RDWGs:**
 - **HHT-WG:** 7 meetings (including 2 face-to-face meetings in Dubrovnik)
 - **HTAD-WG:** 7 meetings (including 1 face-to-face meeting during the ESC Congress in Barcelona, August 2017)
 - **MSA-WG:** 5 meetings
 - **PPL-WG:** 4 meetings
 - **VASCA-WG:** 7 meetings
- **Transversal WGs:**
 - **eHealth-WG:** 4 virtual meetings
 - **Registry-WG:** first meeting in , second face-to-face in Paris & Technical task force meetings
 - **Ethics & communication WGs:** advisory, no meeting yet
- **Patient Group (ePAG):** 6 meetings (+ 2 face-to-face meetings, in Vilnius & during the EURORDIS Congress in Budapest)



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WGs Road Map


**WPs Progresses & Milestones
will be presented during the
session on the state of play of
our action plan!**

Item	Agenda	Action/Decision	Deadlines
	Welcome & Introduction		
	Follow-up last meeting action/decisions		
WP2	Definition of patients pathways		
WP3	Cross-border pathway Mobile APP		
WP4	Pills of knowledge		
WP5	Registries – Safety standards collection & reporting		
WP6	Clinical trials		
WP7	Availability of conferences on YouTube		
WP8	Definition of clinical outcomes		
WP9	Writing recommendations (J1, J2) + transition Child/Adult		
J1	for optimal care of the disease (diagnosis, evaluation, treatment);		
J2	for optimal care of these patients facing common problems not related to their rare diseases		
WP10	Communication & Dissemination activities: messages to VASCERN Project Team and COM-WG		
	Strategic Research Plan – Research Priorities – New Publications - Call for scientific collaborations		
	Cross-ERNs cooperation		
	Partnerships & applications for Membership		
	Funding opportunities		
	AOB		
	Dates of next meetings		
WP 1	Sharing of experience: discussion of difficult clinical cases - HCP Member Representatives only (last 15-20 minutes?)		
1.1	Number of cases discussed during videoconference: Number of cases discussed in the patient case management system: Learnings: Number of summary upload to make: Education material to design from the cases discussion:	ex: XX to write the case summary XX to Upload the summary on the IT Platform	



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Feedback, Q&A and discussion (25')