



# European Reference Network

for rare or low prevalence  
complex diseases

 **Network**  
Vascular Diseases  
(VASCERN)

## ONLINE

# VASCERN DAYS 2020

October 22, 23, 24, 2020

Event Platform: *Whova*

Live Stream Videoconferences system: *WebEx*

 #VASCERNdays2020





# Day 1: Thursday, October 22<sup>nd</sup>

## **8.45-12.05 VASCERN ANNUAL BOARD MEETING**

*Chaired by Guillaume Jondeau and Marine Hurard*

**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*

**9.20-9.35 VASCERN's Enlargement & Cooperations** *(Marine Hurard, Guillaume Jondeau)*

- *Welcome to our New Affiliated Partners 2020*
- *Update on New Healthcare Providers Full Members 2021*
- *National networks of Referral HCPs: sharing good practices (3' per country)*
  - *Netherlands (Leo Schultze Kool & Caroline van den Bosch)*
  - *Sweden (Erik Bjorck)*
  - *France (Guillaume Jondeau for the FAVA-Multi network)*

**9.35-9.45 Inter-ERN Working Group on Legal & Ethical Issues and Relations with Stakeholders: cooperation with the industry** *(Romain Alderweireldt)*

*9.45-10.00 coffee break*

**10.00-11.00 Work Packages**

**10.00-10.35 Implementation** *(7' per RDWG Chair)*

*HHT - Claire Shovlin*  
*HTAD - Julie De Backer*  
*MSA - Leema Robert*  
*PPL - Robert Damstra*  
*VASCA - Miikka Vikkula*

**10.35-11.00 Q&A, sharing best practices & inter-RDWGs projects**

**11.00-11.15 Q&A and approval by the Board**



11.15-11.30 coffee break

11.30-11.45 **European Patient Advocacy Group (ePAG) views, projects & new developments, including Q&A** (ePAG Chair Juergen Grunert & ePAG Co-chairs: Claudia Crocione, Caroline Van Den Bosch, Pernille Henriksen and Elena De Moya Rubio)

11.45-12.05 **Clinical Patient Management System (CPMS)**

- Latest progress, improvements & developments for the simplified CPMS workflow and user-friendly mobile CPMS (Bart Verlinden, European Commission)
- Referral of guest cases: process & examples: Serbia and Portugal (Ibrahim Donmez)

12.05-13.00 lunch break

**13.00-16.00 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS**

HHT-WG ●	HTAD-WG ●	MSA-WG ●	PPL-WG ●	VASCA-WG ●
13.00-14.15 Work Packages	13.00-14.15 Work Packages	13.00-14.15 Work Packages	13.00-14.15 Work Packages	13.00-14.15 Work Packages
14.15-14.30 coffee break				
14.30-16.00: RDWGs CPMS clinical case discussions (clinicians only) MSA/ HTAD shared CPMS clinical cases (MSA joins HTAD meeting)				

16.00-16.15 Council meeting (Chairs only) to select the 5 topics for the Day 2 Brainstorming plenary session



## Day 2: Friday, October 23<sup>rd</sup>

**8.15-8.30 Online connection to Whova and live stream videoconference call**

**08.30-9.00 Research: European Joint Programme on Rare Diseases (EJP RD): calls and opportunities & Q&A** (*Daria Julkowska and Yanis Mimouni*)

*9.00-9.15 coffee break*

**9.15-9.45 VASCERN's Registry WG** *chaired by Leo Schultze Kool*

*Open to all interested members*

*9.45-10.00 break*

**10.00-11.00 Brainstorming on 5 strategic topics selected by the RDWGs** (*12'by topic, each topic discussion moderated by the Chair of the RDWG*)

*11.00-13.00 lunch break*

*Including for the participating members:*

**11.45-12.15 Pregnancy Working Group** *chaired by Julie De Backer*

**13.00-16.00 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS, including interRDWG sessions**

<b>HHT-WG</b> ●	<b>HTAD-WG</b> ●	<b>MSA-WG</b> ●	<b>PPL-WG</b> ●	<b>VASCA-WG</b> ●
13.00-14.30 <i>Work Packages</i>	13.00-14.30 <i>Work Packages</i>	13.00-14.30 <i>Work Packages</i>	13.00-14.30 <i>Work Packages</i>	13.00-14.30 <i>Work Packages</i>
<i>14.30-14.45 coffee break</i>				
14.45-16.00 <i>Work Packages</i>	14.45-16.00 interRDWGs HTAD & MSA <i>(MSA joins HTAD meeting)</i>	14.45-16.00 interRDWGs MSA & HTAD <i>(MSA joins HTAD meeting)</i>	14.45-16.00 interRDWGs PPL & VASCA <i>(PPL joins VASCA meeting)</i>	14.45-16.00 InterRDWGs VASCA & PPL <i>(PPL joins VASCA meeting)</i>

**16.00-16.30 Board plenary: RDWGs' sessions summary outcomes & introducing the way forward (6' per RDWG)**



## Day 3: Saturday, October 24<sup>th</sup>

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

9.00-12.00 PPL & VASCA WORKING GROUPS - PARALLEL SESSIONS

PPL-WG ●	VASCA-WG ●
9.00-10.15 <i>CPMS Clinical Case Discussions (clinicians only)</i>	9.00-10.15 <i>Implementation of Work Packages</i>
10.15-10.30 coffee break	
10.30-11.00 <i>CPMS Clinical Case Discussions (clinicians only)</i>	10.30-12.00 <i>Implementation of Work Packages</i>

12.30-13.30 - European Patient Advocacy Group (ePAG) separate wrap-up, chaired by Juergen Grunert