



**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Vascular Diseases
(VASCERN)

VASCERN DAYS 2019

7-8 November 2019

Brussels, Belgium

Venue & Hotel: *Radisson Blu Royal Hotel, Rue du Fossé aux Loups 47*

All information in: *Practical information kit*



#VASCERNdays2019





Day 1: Thursday, November 7th

8.00-8.30: Registration & Welcome Coffee, foyer of Amsterdam, first floor

8.30-13.00 VASCERN ANNUAL BOARD MEETING

Chaired by Guillaume Jondeau and Marine Hurard

(Amsterdam/Luxembourg, first floor)

8.30-8.35 Welcoming words *(Guillaume Jondeau)*

8.35-9.05 VASCERN's developments

- *Terms of Reference: update and approval (Marine Hurard)*
- *VASCERN's EU co-funding project: update (Marine Hurard)*
- *RDWG F2F meetings formats: sharing best practices (RDWG Chairs)*
- *Monitoring of the ERN and other inter-ERN groups (Marine Hurard, Natasha Barr, Guillaume Jondeau)*
- *Communication and dissemination (Natasha Barr)*

9.05-9.35 VASCERN's enlargement & cooperation

- *New Affiliated Partners 2019 (Marine Hurard)*
- *Call for new HCP Full Membership 2019 (Guillaume Jondeau, Marine Hurard)*
- *interERN cooperation (Guillaume Jondeau)*
- *Brexit*

9.35-9.55 Research: EJP-RD, including Q&A *(Yanis Mimouni)*

9.55-10.10 Coffee break, foyer of Amsterdam, first floor

10.10-11.15 Implementation of Work Packages *(discussion with the RDWG Chairs: Julie De Backer, Leema Robert, Robert Damstra, Miikka Vikkula, Ulrich Sure representing Claire Shovlin, moderated by Marine Hurard) and Q&A, sharing of best practices and interRDWG projects*

11.15-11.35 ePAG feedback and new developments, including Q&A *(Juergen Grunert)*

11.35-11.50 Structure: proposal for reviewing the transversal working groups *(Marine Hurard, Guillaume Jondeau)*



11.50-12.10 **Registries** (*Leo Schultze Kool*)

12.10-12.20 **Ethical and Legal issues** (*Romain Alderweireldt*)

12.20-12.30 **eHealth: Mobile App version 2** (*Alessandro Pini*)

12.30-13.00 **Clinical Patient Management System (CPMS)**

- Progress reports from CPMS team on issues faced (*Caroline Paquier, Hany Mina*)
- Referral of guests cases to VASCERN: how to handle? (*Ibrahim Donmez, Guillaume Jondeau*)

13.00-14.00 Networking lunch, foyer of Amsterdam, first floor

14.00-18.00 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS

HHT-WG ● (Salon 4, 7th floor)	HTAD-WG ● (Amsterdam, 1st floor)	MSA-WG ● (Salon 5, 7th floor)	PPL-WG ● (Salon 3, 7th floor)	VASCA-WG ● (Luxembourg, 1st floor)
<i>Implementation of Work Packages</i>	<i>Implementation of Work Packages</i>	<i>Implementation of Work Packages</i>	<i>Implementation of Work Packages</i> <i>Including: 4.30-5.00: visit of the CPMS team (Caroline Paquier, Hany Mina)</i>	<i>Implementation of Work Packages</i>
<i>16.00-16.15 coffee break, foyer of Amsterdam, first floor</i>				
Including parallel:				
17.00-18.00: RDWGs CPMS case discussions (clinicians only) - Ibrahim Donmez will visit each RDWG				
For HHT: 5.30-6.00: visit of the CPMS team (Caroline Paquier, Hany Mina)				
17.00-18.00: ePAG separate meeting (Salon 2, 7th floor)				

NETWORKING EVENING

19.30 Meeting in front of the hotel

DINNER

20.00 The Kwint

Mont des Arts 1, 1000 Brussels, Belgium



Day 2: Friday, November 8th

8.00-8.30: Registration & Welcome Coffee, foyer of Amsterdam, first floor

8.30-9.30 SHARING OF BEST PRACTICES AND IDEAS IN PLENARY

(Stockholm/Copenhagen, first floor)

Brainstorming around 5 main topics selected on Day 1 by the RDWGs

9.30 Coffee break, foyer of Amsterdam, first floor

9.30-15.30 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS, including 2 hours of interRDWGs sessions

HHT-WG ● (Salon 4, 7th floor)	HTAD-WG ● (Amsterdam, 1st floor)	MSA-WG ● (Salon 5, 7th floor)	PPL-WG ● (Salon 3, 7th floor)	VASCA-WG ● (Luxembourg, 1st floor)
9.30-12.00 <i>Implementation of Work Packages</i>	9.30-12.00 <i>Implementation of Work Packages</i> 10.00-12.00 with MSA (Amsterdam)	9.30-12.00 <i>Implementation of Work Packages</i> 10.00-12.00 with HTAD (Amsterdam)	9.30-12.00 <i>Implementation of Work Packages</i> 10.00-12.00 with VASCA Including a session with Orphanet (Luxembourg)	9.30-12.00 <i>Implementation of Work Packages</i> 10.00-12.00 with PPL, including a session with Orphanet (Luxembourg)
12.00-13.00 <i>Networking lunch, foyer of Amsterdam, first floor</i>				
13.00-15.20 <i>Implementation of Work Packages</i>	13.00-15.20 <i>Implementation of Work Packages</i>	13.00-15.20 <i>Implementation of Work Packages</i>	13.00-15.20 <i>Implementation of Work Packages</i>	13.00-15.20 <i>Implementation of Work Packages</i>

15.20-15.30 coffee break, foyer of Amsterdam, first floor

15.30-16.30 DEBRIEFING AND CONCLUSIONS IN PLENARY SESSION

(Stockholm/Copenhagen, first floor)

15.30-16.20 **Outcomes of the Working Groups' sessions & introducing the way forward** (RDWG Chairs Julie De Backer, Leema Robert, Robert Damstra, Miikka Vikkula, Ulrich Sure representing Claire Shovlin, and ePAG Chair Juergen Grunert - 8' per WG)

16.20-16.30 **Conclusions** (Guillaume Jondeau)

