



European Reference Network

for rare or low prevalence
complex diseases

 **Network**
Vascular Diseases
(VASCERN)

VASCERN DAYS 2021

October 7th, 8th, 9th 2021

Venue: Holiday Inn Canal de la Villette

 #VASCERNdays2021





Day 1: Thursday, October 7th

8.00: DOORS OPENING AND REGISTRATION

8.30-12.05 VASCERN ANNUAL BOARD MEETING

Chaired by Guillaume Jondeau and Julie Hallac

8.30-9.00 **VASCERN's Management & Coordination** (*Julie Hallac, Natasha Barr, Guillaume Jondeau*)

- *Welcoming words*
- *VASCERN Project Team*
- *VASCERN's EU co-funding projects*
- *Communication and dissemination*

9.00-9.30 **VASCERN's developments** (*Julie Hallac, Guillaume Jondeau, Ibrahim Donmez*)

- *eLearning, Moodle platform*
- *subWG guidelines*
- *consent forms*
- *means of communication*
- *Update on New Healthcare Providers Full Members 2021*
- *UK former members' participation*

9.30-10.10 **InterERN WG**

- *Monitoring (Julie or Guillaume) 5'*
- *Guidelines (Guillaume) 5'*
- *Exchange program (Natasha) 10'*
- *Pregnancy WG (Julie De Backer) 10'*
- *ERICA (Mari Murel, project manager) 10'*

10.10-10.30 coffee break

10.30-11.30 **Work Packages**

10.35-11.05 Implementations (7' per RDWG Chair)

HHT - Sophie Dupuis-Girod

HTAD - Julie De Backer

MSA - Michael Franck

PPL - Robert Damstra

VASCA - Miikka Vikkula

11.05-11.30 Q&A, sharing best practices & inter-RDWGs projects



11.30-11.45 **Q&A and approval by the Board**

11.45-12.00 **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)

12.05-13.00 *lunch break*

13.00-17.00 **RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS**

HHT-WG ●	HTAD-WG ●	MSA-WG ●	PPL-WG ●	VASCA-WG ●
13.00-15:15 <i>Work Packages</i>	13.00-15:15 <i>Work Packages</i>	13.00-15:15 <i>Work Packages</i>	13.00-15:15 <i>Work Packages</i>	13.00-15:15 <i>Work Packages</i>
15.15-15.30 <i>coffee break</i>				
15:30-17:00: RDWGs CPMS clinical case discussions (clinicians only)				
15:30-17:00: ePag meeting				

17.00-17.15 **Council meeting (Chairs only) to select the 5 topics for the Day 2 Brainstorming plenary session**

Evening : **Networking dinner in "La Cantine Bretonne" at 19:30. Please refer to the practical info kit for directions.**



Day 2: Friday, October 8th

8.15: DOORS OPENING AND REGISTRATION

08.45-9.30 **Research: European Joint Programme on Rare Diseases (EJP-RD)**

9.30-9.45 coffee break

9.45-10.30 **VASCERN's Registry WG** chaired by *Leo Schultze Kool*

Open to all interested members

10.30-11.30 **Brainstorming on 5 strategic topics selected by the RDWGs** (12' per topic, each topic discussion moderated by the Chair of the RDWG)

11.30-13.00 lunch break à la Criée (Photos)

13.00-17.00 WORKING GROUPS' PARALLEL SESSIONS

13.00-14.30: Registry Working Group meeting chaired by Leo Schultz Kool

13.00-14.30: Pregnancy Working Group chaired by Julie De Backer

13.00-14.30: Prolongation of the brainstorming session

14.30-14.45 coffee break

HHT-WG ●	HTAD-WG ●	MSA-WG ●	PPL-WG ●	VASCA-WG ●
<i>14.45-17.00 Work Packages</i>	<i>14.45-17.00 Work Packages</i>	<i>14.45-17.00 Work Packages</i>	<i>14.45-17.00 Work Packages</i>	<i>14.45-17.00 Work Packages</i>



Day 3: Saturday, October 9th

8.30-11.30 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS, including interRDWG sessions

HHT-WG ●	HTAD-WG ●	MSA-WG ●	PPL-WG ●	VASCA-WG ●
8.30-10.00 <i>Work Packages</i>	8.30-10.00 <i>Work Packages</i>	8.30-10.00 <i>Work Packages</i>	8.30-10.00 <i>Work Packages</i>	8.30-10.00 <i>Work Packages</i>
<i>10.00-10.15 coffee break</i>				
10.15-11.30 <i>Work Packages</i>	10.15-11.30 interRDWGs HTAD & MSA (<i>MSA joins HTAD meeting</i>)	10.15-11.30 interRDWGs MSA & HTAD (<i>MSA joins HTAD meeting</i>)	10.15-11.30 interRDWGs PPL & VASCA (<i>PPL joins VASCA meeting</i>)	10.15-11.30 InterRDWGs VASCA & PPL (<i>PPL joins VASCA meeting</i>)

11.35-12.00 WRAP-UP SESSION

12.15-14.00 lunch break

12.15-13.45 COUNCIL MEETING DURING THE LUNCH BREAK