



# European Reference Network

for rare or low prevalence  
complex diseases

 **Network**  
Vascular Diseases  
(VASCERN)

## VASCERN DAYS 2018

11-12 October 2018

Venue & Hotel: *Holiday Inn Express – Paris Canal de la Villette*

*68, Quai de la Seine - 75019 Paris*

All information in: *Practical information kit*



#VASCERNdays2018





# Day 1: Thursday, October 11<sup>th</sup>

*8.00-8.30: Registration & welcome coffee*

## **8.30-12.30: PLENARY SESSION**

**8.30-8.40: Welcoming words**, Prof Guillaume Jondeau

**8.40-10.00: Board session**, chaired by Prof Guillaume Jondeau and Marine Hurard

Including:

- Structure & participation in Working Group meetings
- Annual assessment of selected ERN HCPs
- InterERN Working Groups progress
  - o IT Advisory Group
  - o Ethical and Legal issues (Romain Alderweireldt)
  - o Research, including EJP-RD (Miikka Vikkula, Claire Shovlin)
  - o Knowledge generation
  - o Monitoring (Enrique Terol, European Commission DG SANTE, Guillaume Jondeau)
- Call for HCP Membership to existing ERNs (2019)
- Revision of RDWG criteria and adding new rare diseases
- VASCERN's grant agreements (EU co-funding) and new EU projects
- Results of the Feedback Survey and discussion
- Q&A on the Terms of References
- Approval
- Challenges and needs for the ERN sustainability and improvement
- Discussion between all stakeholders

*10.00.10.15: Coffee break*

**10.15.10.35: European Patient Advocacy Group (ePAG) developments** including Q&A, Juergen Grunert

**10.35-12.00: Feedback & discussion on progress of the Work Packages for this second year of activities** by the Rare Disease Working Group Chairs (Prof Claire Shovlin, Prof Julie De Backer, Dr Leema Robert, Dr Robert Damstra, Prof Miikka Vikkula) and Transversal WG Chairs (Dr Alessandro Pini, Prof Leo Schultze Kool), moderated by Marine Hurard

**12.00-12.20: Clinical Patient Management System Demonstration**, Hany Mina (OpenApp), Caroline Paquier (European Commission DG SANTE)

- Opening a panel for a multi-disciplinary team
- Completing the patient form and or uploading medical documents/images (including Information about data standards and coding systems used)
- Participating in a panel and making contributions
- Conducting a panel as a panel lead (contributions, draft outcome, sign-off, close and or archive)

*12.30-14.00: Networking lunch in the restaurant area on ground floor*



## 14.00-18.00: RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS

HHT-WG ● <i>Nicolas Ledoux</i>	HTAD-WG ● <i>Seine 1</i>	MSA-WG ● <i>Cours Florent</i>	PPL-WG ● <i>Seine 3</i>	VASCA-WG ● <i>Seine 2</i>
14.00-15.00: Discussion on Work Packages	14.00-15.30: Discussion on Work Packages	14.00-15.00: Discussion on Work Packages	14.00-15.00: Discussion on Work Packages	14.00-16.30: Discussion on Work Packages
15.00-15.30: CPMS Q&A session with OpenApp & DG SANTE, European Commission	15.30-16.00: CPMS Q&A session with OpenApp & DG SANTE, European Commission	16.00-16.30: CPMS Q&A session with OpenApp & DG SANTE, European Commission	15.00-15.30: Discussion with Orphanet on PPL classification	16.00-17.00: Discussion with Orphanet on Vascular anomalies classification
15.30-16.00: Discussion with Orphanet on HHT classification	16.00-17.00: Discussion on Work Packages	16.30-17.00: Discussion on Work Packages	15.30-16.30: Discussion on Work Packages	17.00-17.30: CPMS Q&A session with OpenApp & DG SANTE, European Commission
16.00-17.00: Discussion on Work Packages			16.30-17.00: CPMS Q&A session with OpenApp & DG SANTE, European Commission	
<i>Including parallel:</i>				
17.00-18.00: RDWGs CPMS case discussions (clinicians only)				
17.00-18.00: ePAG meeting ( <i>Jean Vigo</i> )				

### NETWORKING EVENING

18:45

Cocktail (*Nicolas Ledoux*)

20:30

Dinner at Restaurant "Le Laumière"  
4 Rue Petit, 75019 Paris



## Day 2: Friday, October 12th

8.00-8.15: Registration & welcome coffee

### 8.15-10.15: TRANSVERSAL WORKING GROUPS - PARALLEL SESSIONS

eHealth / Training & Education WG <i>Seine 2-3</i>	Patient Registry WG <i>Seine 1</i>
Mobile Application Pills of Knowledge (eLearning) Availability of conferences on YouTube Communication advisory task-force	State of play FAIR principles: VASCA pilot project Other ongoing registry projects RD FAIR network Next steps

10.15-10.30: Coffee break

### 10.30-14.00: RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS

HHT-WG ● <i>Seine 1</i>	HTAD-WG ● <i>Nicolas Ledoux</i>	MSA-WG ● <i>Cours Florent</i>	PPL-WG ● <i>Seine 3</i>	VASCA-WG ● <i>Seine 2</i>
10.30-11.30: Discussion on Work Packages	10.30-11.30: Discussion on Work Packages	10.30-11.30: Discussion on Work Packages, including discussion on FMD & SCAD inclusion	10.30-12.30: Discussion on Work Packages	10.30-11.30: Discussion on Work Packages
11.30-12.30: HHT & VASCA interactive session	11.30-12.30: MSA & HTAD interactive session	11.30-12.30: MSA & HTAD interactive session <i>(Nicolas Ledoux)</i>		11.30-12.30: HHT & VASCA interactive session
12.30-13.00: Business lunch				
13.00-14.00: Discussion on Work Packages	13.00-14.00: Discussion on Work Packages	13.00-14.00: Discussion on European vEDS Cohort with RaDiCo	13:00-14:00: PPL & VASCA interactive session	13.00-14.00: PPL & VASCA interactive session

14.00-14.30: Coffee break



## 14.30-17.00: DEBRIEFING IN PLENARY SESSION

Outcomes of the Working Groups' sessions and introducing the way forward

### Transversal Working Groups Chairs

14.30-14.45: eHealth - Training & Education Working Group, Dr Alessandro Pini

14.45-15.00: Patient Registry Working Group, Prof Leo Schultze Kool

### Rare Disease Working Groups Chairs

15.00-15.15: Hereditary Haemorrhagic Telangiectasia Working Group, Prof Claire Shovlin

15.15-15.30: Heritable Thoracic Aortic Diseases Working Group, Prof Julie De Backer

15.30-15.45: Medium Sized Arteries Working Group, Dr Leema Robert

15.45-16.00: Pediatric and Primary Lymphedema Working Group, Dr Robert Damstra

16.00-16.15: Vascular Anomalies Working Group, Prof Miikka Vikkula

### European Patient Advocacy Group Chair

16.15-16.30: Feedback from the ePAG, Juergen Grunert

16.30-16.45: Discussion with all Members

16.45-17.00: Conclusions, Prof Guillaume Jondeau

