

VASCERN 1st Annual Seminar

Paris, France

13-14 October 2017



Venue & Hotel: Holiday Inn Express – Paris Canal de la Villette
68, Quai de la Seine - 75019 Paris – All information in: Practical information kit

Organised by VASCERN



Supported by the



Supported by the French Network on Rare
Multisystemic Vascular Diseases (FAVA-Multi) and
the French Ministry of Health



MINISTÈRE
DES AFFAIRES SOCIALES,
DE LA SANTÉ
ET DES DROITS DES FEMMES

Day 1: Friday, October 13th

8.00-8.30: Registration & welcome coffee

8.30-12.00: PLENARY SESSION

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

- 31 HCPs Members
- ePAG Patient Organisations
- other stakeholders

9.00-9.45: VASCERN Structure & Organisation: How to build a stronger network? (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, Lenja Wiehe, Matt Johnson)
- Q&A

10.05: coffee break

Photobooth

10.20-11:20: VASCERN 1st year Action Plan: State of play (50')

- Work Packages Objectives & Deliverables (10') (Marine Hurard)
- Feedback from the Council (Coordinator & WGs Chairs) (30')
- 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 (TBC) (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')

12.15-14.00: Lunch

Including Collaborative Platform & CPMS demonstration (TBC)

Photobooth

14.00-16.00: VASCERN BOARD MEETING, chaired by Prof Guillaume Jondeau, Coordinator

*Requested: 1 representative by HCP (31) & ePAG Chairs (6)
Open to all participants without voting rights*

Including:

- Review of the VASCERN Terms of Reference and processes & approval by the Board
- Participation in inter-ERNS WG
- Decisions related to Work Packages & WGs actions, priorities until February 2018 for each WGs
- New ERN Call for new ERN members (December 2017):
 - o Criteria for each RDWG to be revised after the experience of the first year, for the new members
 - o Preference to countries without representatives
- Reporting from WGs Chairs to the Board
- Criteria for an event to be endorsed by VASCERN
- Collaborative platform, CPMS
- Minimal participation to videoconferences & CPMS
- Co-funding
- 2018 annual meeting: date (Doodle: 12-13-14 October 2018 (Thursday-Fri or Fri-Sat))

*16.00-16.15: coffee break
Photobooth*

16.15-16.40: Registry: the FAIR principle (Marco Roos)

16.40-17.00: Debriefing in plenary

17.00-18.00: Patient Group (ePAG) separate meeting

NETWORKING EVENING

18.00-19.00

Cocktail at the seminar venue

20.00

Dinner at the Restaurant « Le Laumière »

4 Rue Petit, 75019 Paris



Day 2: Saturday, October 14th

8.00-8.30: *Registration and coffee*

8.30-8.45: **Welcome & objectives of the WG sessions in plenary by Guillaume Jondeau**

8.45-11.30: PARALLEL 5 RARE DISEASES WORKING GROUPS SESSIONS, chaired by the RDWG Chairs

Some Objectives for all RDWGs:

- Priority & objectives to progress on Work Packages deliverables for 2017
- Identify names of new HCPs Expert centers in EU countries with no Members (extend VASCERN with the new call, favouring new countries)
- Some links, text for patient information in English that we should share, and suggest to translate for new countries
- Patient pathways
- Complex cases discussions: Informed consent & use of the CPMS: state of play & CPMS demonstration (TBC)

10.15-10.30: *coffee break*
Photobooth

HHT-WG	HTAD-WG	MSA-WG	PPL-WG	VASCA-WG
	(TBC) <i>Patient Pathways: finalisation? (Valentina Favalli, Guillaume Jondeau)</i> <i>Derived clinical outcome measures</i> <i>Pills on knowledge (Alessandro Pini)</i> <i>ACTA2 recommendations (Ingrid van de Laar)</i> <i>Update for report to EU: clinical trials, registries</i> <i>New HCPs in new countries</i>			9.00-10.00 Registry: definition of minimal dataset (Leo Schultze-Kool) 10.00-11.00 Orphanet and ICD11 codes for vascular anomalies (Paivi Salminen) 11.00-11.30 New VASCA clinical trials (Laurence Boon)

11.30-13.00: **debriefing in plenary**

13.00-14.00: *Lunch*
Photobooth

**14.00-16.00: PARALLEL TRANSVERSAL WORKING GROUPS SESSIONS,
chaired by the Transversal WGs Chairs**

eHealth - Training & Education WGs	Registry WG
<i>VASCERN Mobile Application: state of play</i> <i>Pills of Knowledge</i>	FAIR principle (Marco Roos)

16.00-16.30: **debriefing in plenary session**

16.30-17.00: *Conclusions, end of the meeting & departure of participants*

Contact: Marine Hurard, +33 1 40 25 80 66, marine.hurard@aphp.fr