

# 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

WIFI: Holiday Inn Express

Password: **meeting1**

## **Day 1: Friday, October 13<sup>th</sup>**

*8.00-8.30: Registration & welcome coffee ("Nicolas Ledoux" room)*

### **8.30-12.15: PLENARY SESSION (« SEINE 1 »)**

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

- 31 HCPs Members
- 12 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, Matt Bolz-Johnson)
- Q&A

*10.05: Coffee break*

*Photo booth (Nicolas Ledoux)*

**10.20-11:20: VASCERN 1<sup>st</sup> year Action Plan: State of play (60')**

- Objectives & state of play of Work packages (Marine Hurard) & Feedback from the Council (Guillaume Jondeau and WGs Chairs: Julie de Backer, Claire Shovlin, Leema Robert, Miikka Vikkula, Sahar Mansour, Alessandro Pini, Leo Schultze Kool, Paolo Federici) (40')
- 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 (Jean-Marie Misztela, Team Leader ERN IT project, European Commission) (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 in the restaurant area on ground floor*

**Including live demonstrations of the Collaborative Platform & the CPMS (Jean-Marie Misztela), next to the restaurant (bar area on ground floor)**

*Photo booth (Nicolas Ledoux)*

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## 14.00-16.00: VASCERN BOARD MEETING, chaired by Prof Guillaume Jondeau, Coordinator (« SEINE 1 »)

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

- Terms of reference for validation by the board (Marine Hurard)
- Priorities for Work Packages: feedback from Chairs
  - RDWG
  - ePAG
  - Transversal WG
- Minimal participation in videoconferences & CPMS
- Funding
- New ERN Call for new ERN members (December 2017):
  - Criteria for each RDWG to be revised after the experience of the first year, for the new members
- Participation in interERN WG
  - Reports from Guillaume Jondeau (Monitoring), Romain Alderweireldt (Ethics)
  - RD-Action work for interERNs cooperation (Victoria Hedley)
- Criteria for an event to be endorsed by VASCERN
- 2018 annual meeting: date (Doodle: 12-13-14 October 2018 (Thursday-Fri or Fri-Sat))
- Questions

*16.00-16.15: coffee break*

*Photo booth (Nicolas Ledoux)*

**16.15-16.40: Registry: the FAIR principle** (Marco Roos) (25')

**16.40-17.00: Debriefing in plenary** (20')

**17.00-18.00: Patient Group (ePAG) separate meeting** (60')

## NETWORKING EVENING

18.00-19.00

Cocktail at the seminar venue (*Nicolas Ledoux*)

20.00

Dinner at the Restaurant « Le Laumière »

*4 Rue Petit, 75019 Paris*



## Day 2: Saturday, October 14<sup>th</sup>

8.00-8.30: *Registration and coffee*

8.30-8.45: **Welcome & objectives of the WG sessions in plenary by Guillaume Jondeau (15')** ("Seine 1" room)

### **8.45-11.30: 5 PARALLEL RARE DISEASES WORKING GROUP SESSIONS, Chaired by the RDWG Chairs**

**Some Objectives for all RDWGs:**

- Priorities & objectives in order to progress on Work Package deliverables
- Identify names of new HCPs/Expert centers in EU countries with no members (extend VASCERN with the new call, favouring new countries)
- Identify any communication material directed towards patients in English that we could share, and/or suggest to translate into other languages
- Patient pathways
- Complex case discussions: Informed consent & use of the CPMS: state of play
- Reporting on ongoing clinical trials

10.15-10.30: *coffee break*

*Photo booth (Nicolas Ledoux)*

<b>HHT-WG ● ("Seine 3" room)</b>	<b>HTAD-WG ● ("Nicolas Ledoux" room)</b>	<b>MSA-WG ● ("Jean Vigo" room)</b>	<b>PPL-WG ● ("Cours Florent" room)</b>	<b>VASCA-WG ● ("Seine 2" room)</b>
Priorities within M12 Structure, Prof Claire Shovlin  Clinical Trials and Pipeline, Dr. Sophie Dupuis Girod  Drug Registry, Prof Elisabetta Buscarini  Registry Progress options  Ethical case discussion  Patient Facing website Materials  Antiplatelet and anticoagulant Guidance  Potential new HCPs in EU countries with no members  AOB Cases #1-7 materials review (by clinicians only) pre uploads	Patient Pathways: finalisation (Valentina Favalli, Prof Guillaume Jondeau)  Derived clinical outcome measures  Pills of knowledge (Dr. Alessandro Pini)  ACTA2 recommendations (Dr. Ingrid van de Laar)  Update for report to EU: clinical trials, registries (Dr. Maarten Groenink)  New HCPs in new countries	Patient Pathways: discussion and format (Juergen Grunert, Dr. Leema Robert)  Research trial: discussion and presentation (Dr. Michael Frank, Prof Xavier Jeunemaitre) Patient passports – discussion (Dr Leema Robert, Juergen Grunert)  Guidelines - Pregnancy in vEDS (Dr Raffaella Gaetano)  Registries – Can we use the format of the French registry or await feedback from registry WG (Prof Xavier Jeunemaitre, Dr. Michael Frank)  Clinical outcomes measures – data collection and when to give feedback  New application invitation for HCPs – the process FMD – when and how to increase participation. Alexandre Persu – should he start preparing documents for inclusion in this category? Questions to Marine?	Patient pathways – Profs Keeley and Mansour will present initial draft for discussion and development  Clinical outcome measures- identify small working group and discuss best measures  Identify names of new HCPs/Expert centers in EU countries with no members  Identify any communication material for patients in English that could be translated into other languages  Complex case discussions: Informed consent & use of the CPMS:  Clinical trials	Registry: definition of minimal dataset (Prof Leo Schultze-Kool)  Orphanet and ICD11 codes for vascular anomalies (Prof Paivi Salminen)  New VASCA clinical trials (Prof Laurence Boon)

11.30-13.00: **debriefing in plenary by RDWG Chairs** (90' - 18' per RDWGs) (*"Seine 1" room*)

*13.00-14.00: Lunch in the restaurant area on ground floor*

*Photo booth (Nicolas Ledoux)*

## **14.00-16.00: 2 PARALLEL TRANSVERSAL WORKING GROUP SESSIONS,**

### **Chaired by the Transversal WG Chairs**

<b>eHealth - Training &amp; Education WG (<i>"Seine 3" room</i>)</b>	<b>Patient Registry WG (<i>"Nicolas Ledoux" room</i>)</b>
VASCERN Mobile Application: state of play Pills of Knowledge Availability of conferences on YouTube	FAIR principle (Dr. Marco Roos) Registry: plans for VASCERN - Common minimum dataset

16.00-16.30: **debriefing in plenary** (30') (*"Seine 1" room*)

*16.30-17.00: Conclusions, end of the meeting & departure of participants. (30') ("Seine 1" room)*

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