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

www.FAVAmulti.fr
Day 1: Friday, October 13th

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 1st 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 Schultzke 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 Eliaszewicz, 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)
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 14th

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)

HHT-WG ● (“Seine 3” room)
- 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

HTAD-WG ● (“Nicolas Ledoux” room)
- Patient Pathways: finalisation (Valentina Favalli, Prof Guillaume Jondeau)
- Derived clinical outcome measures
- Pills of knowledge (Dr. Alessandro Pini)
- ACTAZ recommendations (Dr. Ingrid van de Laar)
- Update for report to EU: clinical trials, registries (Dr. Maarten Groenink)
- New HCPs in new countries

MSA-WG ● (“Jean Vigo” room)
- 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 Raffaela 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?

PPL-WG ● (“Cours Florent” room)
- 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

VASCA-WG ● (“Seine 2” room)
- 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*

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<td>(“Seine 3” room)</td>
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<td>VASCERN Mobile Application: state of play</td>
<td>FAIR principle (Dr. Marco Roos)</td>
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<td>Pills of Knowledge</td>
<td>Registry: plans for VASCERN</td>
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<td>Availability of conferences on YouTube</td>
<td>- Common minimum dataset</td>
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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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