



# European Reference Network

for rare or low prevalence  
complex diseases

 **Network**  
Vascular Diseases  
(VASCERN)

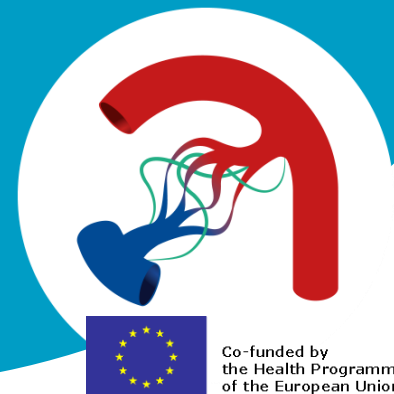
# VASCERN DAYS 2022

October 6<sup>th</sup> & 7<sup>th</sup> 2022

Venue: Espaces Diderot, 10 Rue Traversière, 75012 Paris



#VASCERNdays2022



Co-funded by  
the Health Programme  
of the European Union



# Day 1: Thursday, October 6<sup>th</sup>

## **8.00: DOORS OPENING AND REGISTRATION**

### **8.30-12.05 VASCERN ANNUAL BOARD MEETING**

*Chaired by Guillaume Jondeau and Julie Hallac*

*(Amphithéâtre 103)*

**8.30-8.50 VASCERN's Management & Coordination** *(Julie Hallac, Guillaume Jondeau, Treasure Udechukwu)*

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

**8.50-9.20 VASCERN's developments** *(Julie Hallac, Guillaume Jondeau, Ibrahim Donmez, Romain Alderweireldt)*

- *Training and education : eLearning, Guidelines, Exchange program*
- *Ethics: updates, Conflict of Interest policy*
- *IT developments and means of communication: CPMS, Microsoft Teams*
- *Evaluation: AMEQUIS & monitoring*
- *Extension: Developing partners*

**9.20-9.35 Q&A**

**9.35-10.15 Transversal WGs presentation and Q&A**

- *Pregnancy WG (Julie De Backer) 10'*
- *Registries (Leo Schultze Kool) 30'*

**10.15-10.30 European Patient Advocacy Group (ePAG) views, projects & new developments, patient involvement WG, including Q&A** *(ePAG Chair Claudia Crocione & ePAG Co-chairs: Caroline Van Den Bosch, Pernille Henriksen, Charissa Frank and Elena De Moya Rubio)*

*10.30 -10.45 coffee break*

**10.45-11.15 Research: European Joint Programme on Rare Diseases (EJP-RD)** by Juliane Halftermeyer or Daria Julkowska and Q&A

**11.15-12.00 Work Packages**



**11.15-11.45 Implementations (5' per RDWG Chair)**

*HHT – Sophie Dupuis-Girod  
HTAD - Julie De Backer  
MSA – Michael Frank  
NEUROVASC – Dominique Hervé  
PPL - Robert Damstra  
VASCA - Miikka Viikkula*

**11.45-12.00 Q&A, sharing best practices & inter-RDWGs projects**

**12.00-12.30 Q&A and approval by the Board**

*12.30-13.30 lunch break  
**Group picture in the stairs***

**13.30-14.00: General registry presentation** by Leo Schultze Kool and Pim Kamerling (Amphithéâtre 103)

**13.30-15.00 TRANSVERSAL GROUPS PARALLEL SESSIONS**

*14.00-15.00 : Registry Working Group meeting chaired by Leo Schultze Kool (room 401)  
14.00-15.00: Pregnancy Working Group chaired by Julie De Backer (room 402)  
14.00-15.00: RDWG's search for ideas for the brainstorming session (Amphithéâtre 103)*

*15.00-15.30 coffee break*

**15.30-18.00 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS**

*Discussion on the Work packages*

HHT	HTAD	MSA	NEUROVASC	PPL	VASCA
305	Amphithéâtre 103	404	407	401	402

**Evening**

**19.00 Networking event**



## Day 2: Friday, October 7<sup>th</sup>

**7:45: Arrival of participants**

**8.00: Beginning of the day**

**8.00-9.30 CPMS case discussions & ePAG meeting**

HHT	HTAD	MSA	NEUROVASC	PPL	VASCA	ePAG
305	Amphithéâtre 103	404	407	401	402	307

*9.30-10.00 coffee break*

**10.00-12.00 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS**

*Discussion on the Work packages*

HHT	HTAD	MSA	NEUROVASC	PPL	VASCA
305	Amphithéâtre 103	404	407	401	402

*12.00-13.00 lunch break*

**13.00-16.30 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS**

*Discussion on the Work packages*

HHT	HTAD	MSA	NEUROVASC	PPL	VASCA
305	Amphithéâtre 103	404	407	401	402

*14.45-15.00 coffee break*

*interRDWG sessions*

MSA	HTAD	HHT	NEUROVASC	VASCA	PPL
Amphithéâtre 103		15.00-15.45 : 402			401
		305	407	15.45-16.30 : 402	

**16.30-17.00 Brainstorming session & Closing session in Amphithéâtre 103**