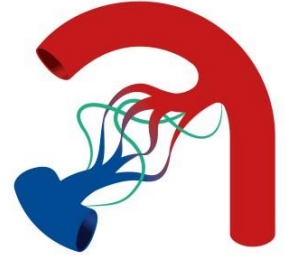




**European  
Reference  
Network**

for rare or low prevalence  
complex diseases

 **Network**  
Vascular Diseases  
(VASCERN)



# VASCERN DAYS 2024

## October 24-25

### Program

October 24<sup>th</sup> & 25<sup>th</sup> 2024

Venue: Novotel CDG Convention

*Agenda might be modified according to needs*





Meeting Online links:

[Program with TEAMS links.pdf](#)

**Certificate of attendance:** You can request a certificate of attendance after the meeting by e-mailing: [Vascern.coordination@aphp.fr](mailto:Vascern.coordination@aphp.fr)



# Day 1 - October 24<sup>th</sup>

## 8.20 DOORS OPENING AND REGISTRATION

### 8.40-12.30 VASCERN ANNUAL BOARD MEETING

Chaired by Prof. Guillaume Jondeau and Julie Hallac- “Navitimer room”

#### 8.40-9.10 VASCERN’s Management & Coordination

*Prof. Guillaume Jondeau, Julie Hallac, Treasure Udechukwu*

- Welcoming words
- VASCERN’s coordination team & past and current grants
- Communication and dissemination
- Evaluation: monitoring, performance indicator system, interERN WG

#### 9.10-9.40 VASCERN’s developments

*Prof. Guillaume Jondeau, Julie Hallac, Gloria Somalo, Roberta Armignacco, Leo Schultze Kool*

- Extension: Developing partners, Ukraine, new call for membership
- Training: CME credits, ERASMUS+, Moodle, clinicians’ mobility
- IT developments and means of communication
- VASCERN rules: Change of Coordinator, Chairs elections, Attendance
- New EU projects: JARDIN & ERDERA

#### 9.40-10.30 Transversal WGs presentation and Q&A

- Pregnancy WG, *Prof. Julie De Backer 10’*
- Registries, *Prof. Leo Schultze Kool and Pim Kamerling, 15’*
- Psychology WG, *Anne-Mette Bredahl, 10’*

#### 10.30 -11.00 coffee break “Espace Pause”

#### 11.00-11.10 European Patient Advocacy Group (ePAG) views, projects & new developments, patient involvement WG, including Q&A

**ePAG Chair: Eva Collado**

**ePAG Co-chairs: Maria Barea, Carmen Quiros, Manuela Lourenço Marques, Paolo Federici, Elisabeth Lisack**

#### 11.10-11.40 Work packages implementations (5’ per RDWG Chair)

**HHT – Dr. Sophie Dupuis-Girod**

**HTAD – Dr. Marlies Kempers**

**MSA – Dr. Michael Frank**

**NEUROVASC – Dr. Dominique Hervé**

**PPL – Dr. Robert Damstra**

**VASCA – Prof. Miikka Vikkula**



11.40-11.50 WPs' Q&A, sharing best practices & potential inter-RDWGs projects

11.50-12.15 Q&A and approval by the Board

12.15-13.45 lunch break “Espace Pause”  
Group picture , place will be defined

13.45-15.15 TRANSVERSAL GROUPS PARALLEL SESSIONS (all open to non-WG members)

- 13.45-15.15 Psychology-WG chaired by Anne-Mette Bredahl and Julie Hallac
- 13.45-15.15 Pregnancy-WG chaired by Prof. Julie De Backer
- 13.45-15.15 Communication-WG chaired by Treasure
- 13.45-15.15 Education-WG chaired by Gloria Somalo and Professor Guillaume Jondeau

Psychology	Pregnancy	Education	Communication
Montbrillant	Navitimer	Chronomat+ Headwind	Datora

15.15-15.45 coffee break “Espace Pause”

15.45-17.15 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS  
Discussion on the Work packages

MSA	HTAD	HHT	NEUROVASC	VASCA	PPL	Psychologists
Crosswind	Navitimer	Montbrillant			Headwind	Datora
		Chronomat	Wings	Montbrillant		

17.15-18.00 Registry technical WG “Wings”

***Prof. Leo J. Schultze Kool, Prof. Guillaume Jondeau, Pim Kamerling, Dr. Sophie Dupuis-Girod, Dr. Robert Damstra, Prof. Miikka Vikkula, Dr. Dominique Hervé***

18.30 Networking event only for ePAGs, APs, HCPs



# Day 2- October 25<sup>th</sup>

8:45 Doors opening

8.00-9.00 Council meeting **Crosswind**

**Coordination team: Professor Guillaume Jondeau, Julie Hallac, Gloria Somalo, Roberta Armignacco**  
**HHT – Dr. Sophie Dupuis-Girod**  
**HTAD – Dr. Marlies Kempers**  
**MSA – Dr. Michael Frank**  
**NEUROVASC – Dr. Dominique Hervé**  
**PPL – Dr. Robert Damstra**  
**VASCA – Prof. Miikka Vikkula**  
**ePAG Chair: Eva Collado**  
**Registries - Prof. Leo J. Schultze Kool**

9.15-10.45 CPMS case discussions & ePAG meeting

HHT	HTAD	MSA	NEUROVASC	PPL	VASCA	ePAG
Chronomat	Olympus	Crosswind	Wings	Headwind	Datora	Blackbird

10.45-11.05 Coffee break **Coffee Lounge**

11.05-12.30 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS  
Discussion on the Work packages

HHT	HTAD	MSA	NEUROVASC	PPL	VASCA
Chronomat	Olympus		Wings	Headwind	Datora

12.30-13.40 lunch break **“Espace Pause”**

13.40-15.10 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS  
Discussion on the Work packages

HHT	HTAD	MSA	NEUROVASC	PPL	VASCA
Chronomat	Olympus	Crosswind	Wings	Headwind	Datora



15.10-15.30 *Coffee break* **Coffee Lounge**

15.30-17.00 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS  
*Discussion on the Work packages*

HHT	HTAD	MSA	NEUROVASC	PPL	VASCA
Chronomat	Olympus	Crosswind	Wings	Headwind	Datora

17.00-17.30 Conclusion and end of the event **Olympus**