




**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Vascular Diseases
(VASCERN)

VASCERN DAYS 2024

October 24-25

Program

October 24th & 25th 2024

Venue: Mercure Charles de Gaulle

Agenda might be modified according to needs



Co-funded by
the Health Programme
of the European Union



Meeting Online links:

Certificate of attendance: You can request a certificate of attendance after the meeting by e-mailing: Vascern.coordination@aphp.fr



Day 1 - October 24th

8.20 DOORS OPENING AND REGISTRATION

8.40-12.30 VASCERN ANNUAL BOARD MEETING

Chaired by Prof. Guillaume Jondeau (Department of Cardiology, Bichat Hospital, Assistance Publique-Hopitaux de Paris, Paris, France) and Julie Hallac (VASCERN Project Manager) - Plenary

8.40-9.10 VASCERN's Management & Coordination

Prof. Guillaume Jondeau (Department of Cardiology, Bichat Hospital, Assistance Publique-Hopitaux de Paris, Paris, France), Julie Hallac (VASCERN Project Manager), Treasure Udechukwu (VASCERN Project Officer)

- Welcoming words
- VASCERN's coordination team and current grant
- Communication and dissemination (Mobile app)
- Evaluation: monitoring, performance indicator system

9.10-9.40 VASCERN's developments

Prof. Guillaume Jondeau (Department of Cardiology, Bichat Hospital, Assistance Publique-Hopitaux de Paris, Paris, France), Julie Hallac (VASCERN Project Manager), Gloria Somalo (VASCERN Project Officer), Leo Schultze Kool (Department of Medical Imaging, Radboud University Medical Center, Nijmegen, Netherlands), Romain Alderweireldt (Association Belge du Syndrome de Marfan (ABSM)).

- Extension: Developing partners, Ukraine, new call for membership
- Training and education: CME credits, Summer school
- IT developments and means of communication: new CPMS
- VASCERN rules: Change of Coordinator, Chair, attendance
- New EU projects: JARDIN & ERDERA

9.40-10.30 Transversal WGs presentation and Q&A

- Pregnancy WG, *Prof. Julie De Backer (Department of Cardiology, Ghent University Hospital, Gent, Belgium) 10'*
- Registries, *Prof. Leo Schultze Kool (Department of Medical Imaging, Radboud University Medical Center, Nijmegen, Netherlands) and Pim Kamerling (VASCERN Data Steward), 15'*
- Psychology WG, *Anne-Mette (TRS, Oslo, Norway), 10'*

10.30 -11.00 coffee break **Coffee Lounge**



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

ePAG Chair: Eva Collado (ANSEDH – Spanish National Patient Organization for Ehlers-Danlos, Spain)

ePAG Co-chairs: Maria Barea (VASCAPA, Belgium), **Carmen Quiros** (Asociacion Española de Afectados por el Síndrome de Marfan (SIMA), Spain), **Manuela Lourenço Marques** (Associação Nacional de Doentes Linfáticos (andLINFA), Portugal), **Paolo Federici** (HHT Italy).

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

HHT – Dr. Sophie Dupuis-Girod (Hospices Civils de Lyon, Service de Génétique, Groupement Hospitalier Est, Bron, France)

HTAD – Dr. Marlies Kempers (Department of Clinical Genetics, Radboud University Medical Center, Nijmegen, The Netherlands.)

MSA – Dr. Michael Frank (Hopital Europeen Georges Pompidou, APHP, Departement de Genetique et Centre de Reference des Maladies Vasculaires Rares, Paris, France)

NEUROVASC – Dr. Dominique Hervé (CNVT - CERVCO and Neurology, Hopital Lariboisiere, APHP, Paris, France)

PPL – Dr. Robert Damstra (Expert Center for Lymphovascular Medicine, Nij Smellinghe Hospital, Drachten, the Netherlands)

VASCA – Prof. Miikka Vikkula (Center for Vascular Anomalies, Division of Plastic Surgery, University Clinics Saint-Luc, University of Louvain, Brussels, Belgium; VASCERN VASCA European Reference Centre) and **Prof. Leo J. Schultze Kool** (Department of Medical Imaging, Radboud University Medical Center, Nijmegen, Netherlands)

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

11.50-12.15 Q&A and approval by the Board

12.15-13.45 lunch break **Coffee Lounge**
Group picture **In front of the building**

13.45-15.15 TRANSVERSAL GROUPS PARALLEL SESSIONS (not specific to groups' members except Registry)

- **13.45-15.15** Psychology thematic brainstorm chaired by Julie Hallac (VASCERN Project Manager)
- **13.45-15.15** Pregnancy Working Group chaired by Prof. Julie De Backer (Department of Cardiology, Ghent University Hospital, Gent, Belgium)
- **13.45-15.15** Communication thematic brainstorm chaired by Treasure (VASCERN Project Officer)
- **13.45-15.15** Education thematic brainstorm chaired by Roberta Armignacco (VASCERN Project Officer)



Psychology	Pregnancy	Psychology	Communication
Classroom	Orangerie	Maritime Room	Library

15.15-15.45 coffee break **Coffee Lounge**

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

HHT – Dr. Sophie Dupuis-Girod (Hospices Civils de Lyon, Service de Génétique, Groupement Hospitalier Est, Bron, France)

HTAD – Dr. Marlies Kempers (Department of Clinical Genetics, Radboud University Medical Center, Nijmegen, The Netherlands.)

MSA – Dr. Michael Frank (Hopital Europeen Georges Pompidou, APHP, Departement de Genetique et Centre de Reference des Maladies Vasculaires Rares, Paris, France)

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VASCA – Prof. Miikka Vikkula (Center for Vascular Anomalies, Division of Plastic Surgery, University Clinics Saint-Luc, University of Louvain, Brussels, Belgium; VASCERN VASCA European Reference Centre)

HHT	HTAD	MSA	NEUROVASC	PPL	VASCA
Winter Garden	Orangerie	Music Room	Gaming Room	Library	Class Room

17.15-18.00 Registry technical WG

Dr. Sophie Dupuis-Girod (Hospices Civils de Lyon, Service de Génétique, Groupement Hospitalier Est, Bron, France)

Dr. Robert Damstra (Expert Center for Lymphovascular Medicine, Nij Smellinghe Hospital, Drachten, the Netherlands)

Prof. Leo J. Schultze Kool (Department of Medical Imaging, Radboud University Medical Center, Nijmegen, Netherlands)

Prof. Miikka Vikkula (Center for Vascular Anomalies, Division of Plastic Surgery, University Clinics Saint-Luc, University of Louvain, Brussels, Belgium; VASCERN VASCA European Reference Centre)

Prof. Guillaume Jondeau (Department of Cardiology, Bichat Hospital, Assistance Publique-Hopitaux de Paris, Paris, France)

Dr. Dominique Hervé (CNVT - CERVCO and Neurology, Hopital Lariboisiere, APHP, Paris, France)

Pim Kamerling (VASCERN Data Steward)

18.30 Networking event only for ePAGs, APs, HCPs



Day 2- October 25th

8:45 Doors opening

8.00-9.00 Council meeting

HHT – Dr. Sophie Dupuis-Girod (Hospices Civils de Lyon, Service de Génétique, Groupement Hospitalier Est, Bron, France)

HTAD – Dr. Marlies Kempers (Department of Clinical Genetics, Radboud University Medical Center, Nijmegen, The Netherlands.)

MSA – Dr. Michael Frank (Hopital Europeen Georges Pompidou, APHP, Departement de Genetique et Centre de Reference des Maladies Vasculaires Rares, Paris, France)

NEUROVASC – Dr. Dominique Hervé (CNVT - CERVCO and Neurology, Hopital Lariboisiere, APHP, Paris, France)

PPL – Dr. Robert Damstra (Expert Center for Lymphovascular Medicine, Nij Smellinghe Hospital, Drachten, the Netherlands)

VASCA – Prof. Miikka Vikkula (Center for Vascular Anomalies, Division of Plastic Surgery, University Clinics Saint-Luc, University of Louvain, Brussels, Belgium; VASCERN VASCA European Reference Centre) and **Prof. Leo J. Schultze Kool** (Department of Medical Imaging, Radboud University Medical Center, Nijmegen, Netherlands)

ePAG Chair: Eva Collado (ANSEDH – Spanish National Patient Organization for Ehlers-Danlos, Spain)

Ethics – Chair: Romain Alderweireldt (Association Belge du Syndrome de Marfan (ABSM))

9.15-10.45 CPMS case discussions & ePAG meeting

HHT – Dr. Sophie Dupuis-Girod (Hospices Civils de Lyon, Service de Génétique, Groupement Hospitalier Est, Bron, France)

HTAD – Dr. Marlies Kempers (Department of Clinical Genetics, Radboud University Medical Center, Nijmegen, The Netherlands.)

MSA – Dr. Michael Frank (Hopital Europeen Georges Pompidou, APHP, Departement de Genetique et Centre de Reference des Maladies Vasculaires Rares, Paris, France)

NEUROVASC – Dr. Dominique Hervé (CNVT - CERVCO and Neurology, Hopital Lariboisiere, APHP, Paris, France)

PPL – Dr. Robert Damstra (Expert Center for Lymphovascular Medicine, Nij Smellinghe Hospital, Drachten, the Netherlands)

VASCA – Prof. Miikka Vikkula (Center for Vascular Anomalies, Division of Plastic Surgery, University Clinics Saint-Luc, University of Louvain, Brussels, Belgium; VASCERN VASCA European Reference Centre) and **Prof. Leo J. Schultze Kool** (Department of Medical Imaging, Radboud University Medical Center, Nijmegen, Netherlands)

ePAG – Eva Collado (ANSEDH – Spanish National Patient Organization for Ehlers-Danlos, Spain)



HHT	HTAD	MSA	NEUROVASC	PPL	VASCA	ePAG
Winter Garden	Orangerie	Music Room	Gaming Room	Library	Class Room	Machine Room

10.45-11.05 Coffee break **Coffee Lounge**

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

HHT – Dr. Sophie Dupuis-Girod (Hospices Civils de Lyon, Service de Génétique, Groupement Hospitalier Est, Bron, France)

HTAD – Dr. Marlies Kempers (Department of Clinical Genetics, Radboud University Medical Center, Nijmegen, The Netherlands.)

MSA – Dr. Michael Frank (Hopital Europeen Georges Pompidou, APHP, Departement de Genetique et Centre de Reference des Maladies Vasculaires Rares, Paris, France)

NEUROVASC – Dr. Dominique Hervé (CNVT - CERVCO and Neurology, Hopital Lariboisiere, APHP, Paris, France)

PPL – Dr. Robert Damstra (Expert Center for Lymphovascular Medicine, Nij Smellinghe Hospital, Drachten, the Netherlands)

VASCA – Prof. Miikka Vikkula (Center for Vascular Anomalies, Division of Plastic Surgery, University Clinics Saint-Luc, University of Louvain, Brussels, Belgium; VASCERN VASCA European Reference Centre) and **Prof. Leo J. Schultze Kool** (Department of Medical Imaging, Radboud University Medical Center, Nijmegen, Netherlands)

HHT	HTAD	MSA	NEUROVASC	PPL	VASCA
Winter Garden	Orangerie	Music Room	Gaming Room	Library	Class Room

12.30-13.40 lunch break **Coffee Lounge**

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

HHT – Dr. Sophie Dupuis-Girod (Hospices Civils de Lyon, Service de Génétique, Groupement Hospitalier Est, Bron, France)

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HHT	HTAD	MSA	NEUROVASC	PPL	VASCA
Winter Garden	Orangerie	Music Room	Gaming Room	Library	Class Room

15.10-15.30 Coffee break **Coffee Lounge**

15.30-17.00 interRDWG SESSIONS

HHT – Dr. Sophie Dupuis-Girod (Hospices Civils de Lyon, Service de Génétique, Groupement Hospitalier Est, Bron, France) and **Prof. Elisabetta Buscarini** (Gastroenterology and Endoscopy Department, ASST Crema 'Maggiore' Hospital, Crema, Italy)

HTAD – Prof. Julie De Backer (Department of Cardiology, Ghent University Hospital, Gent, Belgium)

MSA – Dr. Michael Frank (Hopital Europeen Georges Pompidou, APHP, Departement de Genetique et Centre de Reference des Maladies Vasculaires Rares, Paris, France)

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MSA	HTAD	HHT	NEUROVASC	VASCA	PPL
Music Room	Orangerie	Winter Garden	Gaming Room	Class Room	Library
16.30-17.00 Orangerie				16.15-17.00 Classroom	

17.00-17.30 Conclusion and end of the event
Orangerie