



European Reference Network

for rare or low prevalence
complex diseases

 **Network**
Vascular Diseases
(VASCERN)

VASCERN DAYS 2023

October 5th & 6th 2023

Venue: Maison de la Poste, Brussels



#VASCERNdays2023



Co-funded by
the Health Programme
of the European Union



Day 1: Thursday, October 5th

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 (AP-HP), Paris, France) and **Julie Hallac** (VASCERN Project Manager) - **Maritime Room**

8.40-9.00 VASCERN's Management & Coordination

Julie Hallac (VASCERN Project Manager), Prof. Guillaume Jondeau (Department of Cardiology, Bichat Hospital, AP-HP, Paris, France), Treasure Udechukwu (VASCERN Project Officer)

- Welcoming words
- VASCERN's EU funded projects
- Communication and dissemination

9.00-9.30 VASCERN's developments

Julie Hallac (VASCERN Project Manager), Prof. Guillaume Jondeau (Department of Cardiology, Bichat Hospital, AP-HP, Paris, France), Ibrahim Donmez (VASCERN Project Officer), Gloria Somalo (VASCERN Project Officer)

- Training and education : Guidelines, Exchange program, Summer school
- IT developments and means of communication: CPMS, Microsoft Teams
- Evaluation: AMEQUIS & monitoring
- Extension: Developing partners
- VASCERN rules: Modification within a team / Chair, Cochair change
- New EU projects: JARDIN & Rare Disease Partnership

9.30-10.30 Transversal WGs presentation and Q&A

- Pregnancy WG. **Prof. Julie De Backer** (Department of Cardiology, Ghent University Hospital, Ghent, Belgium) 10'
- Registries. **Prof. Leo Schultze Kool** (Department of Medical Imaging, Radboud University Medical Center, Nijmegen, Netherlands) and **Pim Kamerling** (VASCERN Data Steward) 45'

10.30 -11.00 coffee break **Coffee Lounge**

11.00-11.15 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), **Christina Grabowski** (Morbus Osler Selbsthilfe e. V, Germany)

11.15-12.00 Work Packages

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

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

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)

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)

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

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

12.30-14.00 lunch break **Coffee Lounge**
Group picture **In front of the building**

14.00-15.00 **TRANSVERSAL GROUPS PARALLEL SESSIONS**

(specific to group members)

14.10-15.10: **Psychology Working Group Classroom**

14.10-15.10: **Pregnancy Working Group Orangerie**

14.10-15.10: **Brainstorming session Maritime Room**

15.00-15.30 coffee break **Coffee Lounge**

15.30-17.30 **RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS**

Discussion on the Work packages

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

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)

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17.45-18.45 Registries Technical team meeting (Library)

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, AP-HP, Paris, France)

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

Pim Kamerling (VASCERN Data Steward)

Allyre Lohier (AP-HP, Paris, France)

Claire Batista (AP-HP, Paris, France)

Nouha Ghourabi (AP-HP, Paris, France)

Jean-Phillipe Allard (Registry Developer, Hospices Civils de Lyon, Groupement Hospitalier Est, Bron, France)

Evelyne Decullier (Registry Project Manager, Hospices Civils de Lyon, Groupement Hospitalier Est, Bron, France)

19.00 Networking event



Day 2: Friday, October 6th

8:45: Doors opening

9.15-10.45 CPMS case discussions & ePAG meeting

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

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)

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

10:45-11:00 coffee break **Coffee Lounge**

11.00-12.30 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS

Discussion on the Work packages (**same rooms**)

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)

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



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12.30-13.30 lunch break **Coffee Lounge**

13.30-15.00 RARE DISEASE WORKING GROUPS - PARALLEL SESSIONS

Discussion on the Work packages (**same rooms**)

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)

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15.00-15.30 coffee break **Coffee Lounge**

15.30-17.00 interRDWG SESSIONS

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

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)

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

Council Meeting (1h, at 7.00 – only for Chairs)

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

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

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



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In this context, Leo J. Schultze Kool, professor at the Department of Medical Imaging of the Radboud University Medical Center in Nijmegen, Netherlands, and member of the Scientific and Organizing Committee of the VASCERN Days 2023, declares a potential conflict of interest. Prof. Leo J. Schultze Kool is the recipient of the Network Support Scheme, granted by the EJP-RD in 2023.