

VASCERN 1st Annual Seminar

Rare Disease and Transversal Working Group lists

Rare Disease Working Groups (RDWGs)

Hereditary Haemorrhagic Telangiectasia (HHT)-WG,

Chaired by Prof. Claire SHOVLIN

Denmark	Prof. Anette KJELDEN	Odense University Hospital	Member
	Dr Pernille MATHIESEN TØRRING		Member
France	Dr Sophie DUPUIS-GIROD	Hospices Civils de Lyon	Co-chair
France	Didier ERASME	AMRO (HHT France)	ePAG Member
Germany	Prof. Urban GEISTHOFF	Essen University Hospital	Member
	Dr Freya DROEGE		Member

Germany	Christina GRABOWSKI	Morbus Osler	ePAG Representative
Italy	Prof. Elisabetta BUSCARINI	ASST Ospedale Maggiore Crema	Deputy Co-chair
Italy	Paolo FEDERICI	HHT Onilde Carini	ePAG Chair
Italy	Prof Carlo SABBÀ	Azienda Ospedaliero- Universitaria Consorziale di Bari Policlinico-Giovanni XXIII Bari	Member
	Dr Gennaro Mariano LENATO		Member
Italy	Dr Sara UGOLINI	IRCCS Foundation Policlinico San Matteo	Member
Netherlands	Dr Hans-Jurgen MAGER	St. Antonius Hospital	Member
Spain	Luisa BOTELLA	HHT Espana	ePAG Representative
UK	Prof. Claire SHOVLIN	Hammersmith Hospital, Imperial College Healthcare NHS Trust	Chair
	Dr Nicky COOTE		Member
16 PARTICIPANTS			

Heritable Thoracic Aortic Disease (HTAD)-WG

Chaired by Prof. Guillaume JONDEAU

Belgium	Romain ALDERWEIRELDT	ABSM Association Belge du Syndrome de Marfan	ePAG Representative
Belgium	Dr Liesbeth WILDERO - VAN WOUWE	Ghent University Hospital	Member (substitute representative for Prof. Julie DE BACKER (Chair))
Belgium	Prof. Bart LOEYS	UZA-Antwerp University Hospital	Member
France	Dr Claire BOULETI	AP-HP, Hôpital Bichat-Claude Bernard	Member
	Prof. Guillaume JONDEAU		Member
	Dr Olivier MILLERON		Co-chair
			Member
France	Patrice TOUBOULIE	MARFANS	ePAG Representative
Germany	Dr Christian BEHRENDT	University Medical Center Hamburg-Eppendorf	Member
Hungary	Prof. Zoltan SZABOLCS	Semmelweis University, Heart and Vascular Center	Member

	Dr Kalman BENKE		Member
Italy	Prof. Guglielmina PEPE	Careggi Hospital	Member
	Prof. Betti GIUSTI		Member
Italy	Dr Alessandro PINI	ASST Fatebenefratelli-Sacco	Member
Italy	Valentina FAVALLI	Magica Onlus	ePAG Co-chair for HTAD
Italy	Dr Alessandra SERIO	IRCCS Foundation Policlinico San Matteo	Member
	Dr Alessandro DI TORO		Member
Netherlands	Prof. Maarten GROENINK	AMC Amsterdam	Member
	Dr Vivian DE WAARD		Member
Netherlands	Dr Marlies KEMPERS	Radboud University Medical Center	Member
Netherlands	Dr Ingrid Van DE LAAR	Erasmus Medical Center Rotterdam	Member

Sweden	Dr Erik BJORCK	Karolinska University Hospital	Member
UK	Dr Yaso EMMANUEL	Guy's and St Thomas' NHS Foundation Trust	Member
22 participants			

Medium Sized Arteries (MSA)-WG

Chaired by Dr Leema ROBERT

France	Prof. Xavier JEUNEMAITRE	APHP HEGP Hôpital Européen Georges Pompidou	Co-chair
	Dr Michael FRANK		Member
Germany	Juergen GRUNERT	Ehlers-Danlos-Initiative e.V.	ePAG Co-chair for MSA
Italy	Dr Alessia PAGLIALONGA	ASST Fatebenefratelli-Sacco	Member
	Dr Raffaella GAETANO		Member
Netherlands	Dr Ingrid Van DE LAAR	Erasmus Medical Center Rotterdam	Member
UK	Dr Leema ROBERT	Guy's and St Thomas' NHS Foundation Trust	Chair
7 Participants			

Pediatric and Primary Lymphedema (PPL)-WG

Chaired by Prof. Sahar MANSOUR

Belgium	Dr Guido GIACALONE	AZ Sint-Maarten	Member
	Dr Florence BELVA		
Belgium	Dr Sarah THOMIS	University Hospitals Leuven	Member
	Dr Nele DEVOOGDT		Member
Finland	Prof. Sinikka SUOMINEN	Helsinki University Hospital	Member
France	Dr Stéphane VIGNES	HEGP: Cognacq-Jay Hospital, Paris	Member
Netherlands	Natascha ASSIES	NLNet	ePAG Co-chair for PPL
Netherlands	Dr Kirsten VAN DUINEN	Drachten Hopital (Nij Smellinghe Hospital)	Member (substitute representative for Dr Robert DAMSTRA (Chair))
UK	Dr Vaughan KEELEY	Derby Teaching Hospitals NHS Foundation Trust	Member
	Katie RICHES		Member
UK	Prof. Sahar MANSOUR	St George's Hospital	Co-chair
11 PARTICIPANTS			

Vascular Anomalies (VASCA)-WG

Chaired by Prof. Miikka VIKKULA

Belgium	Prof. Laurence BOON	Cliniques Universitaires Saint-Luc	Chairs
	Prof. Miikka VIKKULA		
Belgium	Franziska HAIML	VASCAPA	ePAG Member
Finland	Prof. Päivi SALMINEN	Helsinki University Hospital	Member
Germany	Prof. Jochen RÖSSLER	Medical Center - University Freiburg	Member
Ireland	Dr Veronika DVORAKOVA	Our Lady's Children's Hospital Crumlin	Member
Italy	Dr Andrea DIOCIUTI	Bambino Gesù Children Hospital	Member
Netherlands	Prof. Leo SCHULTZE KOOL	Radboud University Medical Center	Co-chair
Netherlands	Caroline VAN DEN BOSCH	HEVAS	ePAG Co-chair for VASCA
Netherlands	Ange VAN DER VELDEN	LGD Alliance Europe (LGD Alliance Nederland)	ePAG Representative
Sweden	Dr Nader GHAFARPOUR	Karolinska University Hospital	Member
11 participants			

Patient Group (ePAG)

Chaired by Mr Paolo FEDERICI

Belgium	Romain ALDERWEIRELDT	ABSM Association Belge du Syndrome de Marfan	Ethics WG Chair/ ePAG Representative
Belgium	Franziska HAIML	VASCAPA	ePAG Member
France	Didier ERASME	AMRO (HHT France)	ePAG Member
France	Patrice TOUBOULIE	MARFANS	ePAG Representative
Germany	Christina GRABOWSKI	Morbus Osler	ePAG Representative
Germany	Jurgen GRUNERT	Ehlers-Danlos-Initiative e.V.	ePAG Co-chair for for MSA
Italy	Valentina FAVALLI	Magica Onlus	ePAG Co-chair for HTAD
Italy	Paolo FEDERICI	HHT Onilde Carini	ePAG Chair
Netherlands	Natascha ASSIES	NLNet	ePAG Co-chair for PPL
Netherlands	Caroline VAN DEN BOSCH	HEVAS	ePAG Co-chair for VASCA
Netherlands	Ange VAN DER VELDEN	LGD Alliance Europe (LGD Alliance Nederland)	ePAG Representative
Spain	Luisa BOTELLA	HHT Espana	ePAG Representative
12 participants			

Transversal Working Groups

E-health & Training and Education WG

Chaired by Dr Alessandro PINI (E-health)
Co-chaired by Prof. Jochen RÖSSLER (Training and Education)

Belgium	Dr Florence BELVA	AZ Sint-Maarten	Member
Belgium	Franziska HAIML	VASCAPA	ePAG Member
Belgium	Dr Liesbeth WILDERO - VAN WOUWE	Ghent University Hospital	Member
Belgium	Dr Sarah THOMIS	University Hospitals Leuven	Member
Finland	Prof. Päivi SALMINEN	Helsinki University Hospital	eHealth Co-chair
France	Prof. Xavier JEUNEMAITRE	APHP, HEGP Hôpital Européen Georges Pompidou	Member
	Dr Michael FRANK		Member
Germany	Dr Freya DROEGE	Essen University Hospital	Member

Germany	Prof. Jochen RÖSSLER	Medical Center - University Freiburg	T&E Chair
Italy	Prof. Elisabetta BUSCARINI	ASST Ospedale Maggiore Crema	Member
Italy	Dr Andrea DIOCIAIUTI	Bambino Gesù Children Hospital	Member
Italy	Valentina FAVALLI	Magica Onlus	ePAG Representative
Italy	Paolo FEDERICI	HHT Onilde Carini	ePAG Chair
Italy	Prof. Betti GIUSTI	Careggi Hospital	Member
Italy	Dr Alessandro PINI	ASST Fatebenefratelli-Sacco	eHealth Chair
	Dr Alessia PAGLIALONGA		Member
Italy	Prof Carlo SABBÀ	Azienda Ospedaliero-Universitaria Consorziale di Bari Policlinico-Giovanni XXIII Bari	Member
	Dr Gennaro Mariano LENATO		Member
Italy	Dr Alessandra SERIO	IRCCS Foundation Policlinico San Matteo	Member
	Dr Alessandro DI TORO		Member
Italy	Dr Sara UGOLINI	IRCCS Foundation Policlinico San Matteo	Member
Netherlands	Natascha ASSIES	NLNet	ePAG Representative

Netherlands	Dr Hans-Jurgen MAGER	St. Antonius Hospital	Member
Netherlands	Caroline VAN DEN BOSCH	HEVAS	ePAG Co-chair
Netherlands	Ange VAN DER VELDEN	LGD Alliance Europe (LGD Alliance Nederland)	ePAG Representative
Spain	Luisa BOTELLA	HHT Espana	ePAG Representative
UK	Prof. Claire SHOVLIN	Hammersmith Hospital, Imperial College Healthcare NHS Trust	Member
	Dr Nicky COOTE		Member
UK	Dr Leema ROBERT	Guy's and St Thomas' NHS Foundation Trust	Chair
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Patient Registry WG

Chaired by Prof. Leo SCHULTZE KOOL

Belgium	Romain ALDERWEIRELDT	ABSM Association Belge du Syndrome de Marfan	Member/Ethics WG Chair
Belgium	Prof. Laurence BOON	Cliniques Universitaires Saint-Luc	Member
	Prof. Miikka VIKKULA		Member
Belgium	Dr Guido GIACALONE	AZ Sint-Maarten	Member
Belgium	Prof. Bart LOEYS	UZA-Antwerp University Hospital	Member
Belgium	Dr Nele DEVOOGDT	University Hospitals Leuven	Member
Denmark	Prof. Anette KJELDSSEN	Odense University Hospital	Member
	Dr Pernille MATHIESEN TØRRING		Member
France	Dr Sophie DUPUIS-GIROD	Hospices Civils de Lyon	Member
France	Didier ERASME	AMRO (HHT France)	ePAG Member
France	Prof. Guillaume JONDEAU	AP-HP, Hôpital Bichat-Claude Bernard	Member

France	Patrice TOUBOULIE	MARFANS	ePAG Representative
France	Dr Stéphane VIGNES	HEGP :Cognacq-Jay Hospital, Paris	Member
France	Jérôme WEINBACH	RADICO	Member
Germany	Dr Christian BEHRENDT	University Medical Center Hamburg-Eppendorf	Member
Germany	Prof. Urban GEISTHOFF	Essen University Hospital	Member
Germany	Christina GRABOWSKI	Morbus Osler	ePAG Representative
Germany	Juergen GRUNERT	Ehlers-Danlos-Initiative e.V.	ePAG Co-chair for MSA
Hungary	Prof. Zoltan SZABOLCS	Semmelweis University, Heart and Vascular Center	Member
	Dr Kalman BENKE		Member
Ireland	Dr Veronika DVORAKOVA	Our Lady's Children's Hospital Crumlin	Member
Italy	Dr Raffaella GAETANO	ASST Fatebenefratelli-Sacco	Member
Italy	Prof. Guglielmina PEPE	Careggi Hospital	Member
Netherlands	Dr Marlies KEMPERS	Radboud University Medical Center	Member

Netherlands	Prof. Leo SCHULTZE KOOL	Radboud University Medical Center	Chair
Netherlands	Dr Marco ROOS	Leiden University Medical Centre	Member
Netherlands	Dr Ingrid Van DE LAAR	Erasmus Medical Center Rotterdam	Member
Netherlands	Dr Kirsten VAN DUINEN	Drachten Hopital (Nij Smellinghe Hospital)	Member
UK	Dr Yaso EMMANUEL	Guy's and St Thomas' NHS Foundation Trust	Member
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