VASCern

The European Network on Rare Multisystemic Vascular Diseases

MEMBERS
GOVERNANCE
STRUCTURE
WORKING GROUPS

September 2016

VASCern
HCP Member Applicants

Full list available on the Directory of HCP Members

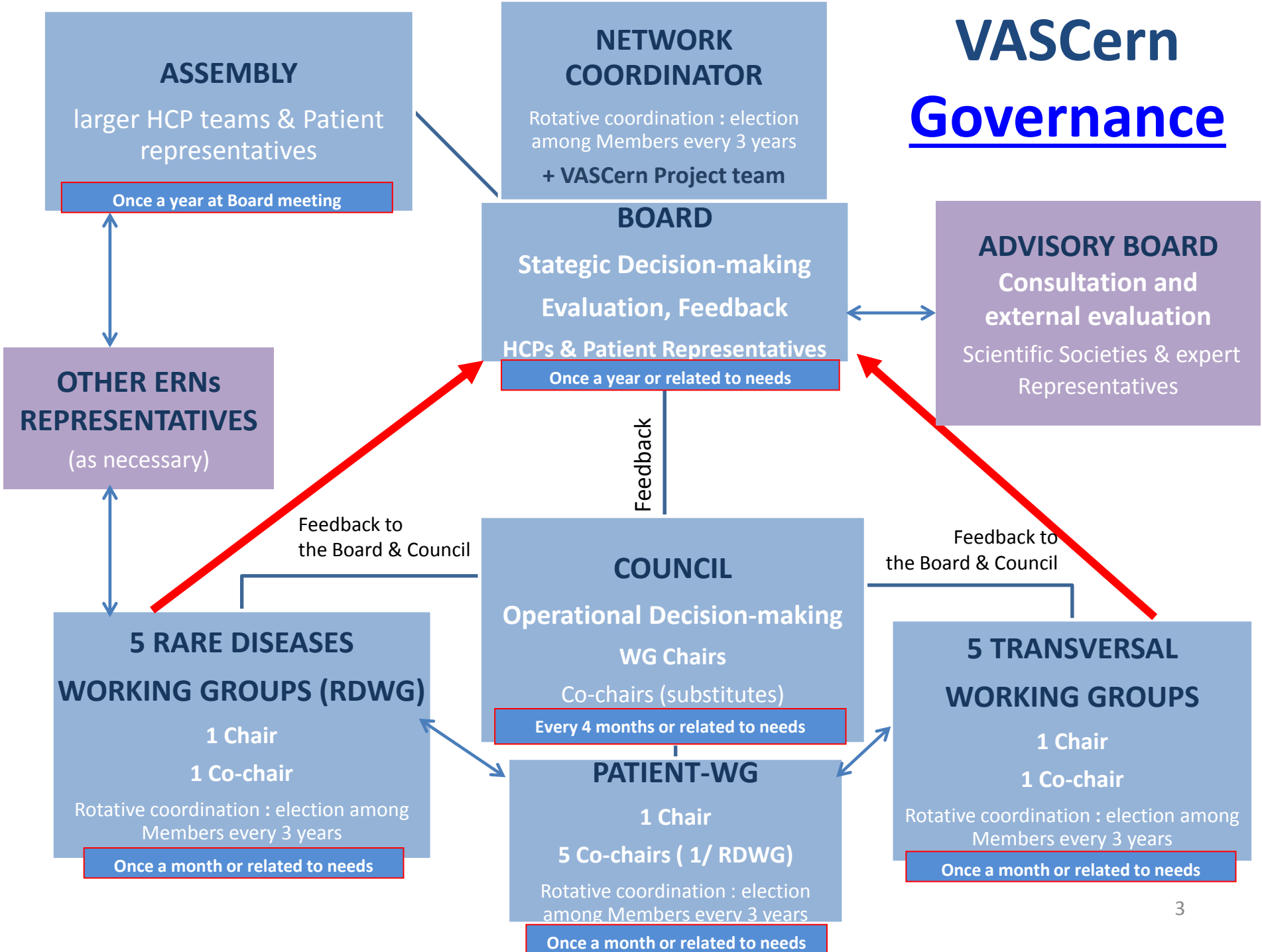
31 Healthcare Providers…

… from **11 European Union Member States**

(Belgium, Denmark, Finland, France, Germany, Hungary, Ireland, Italy, Netherlands, United Kingdom, Sweden)

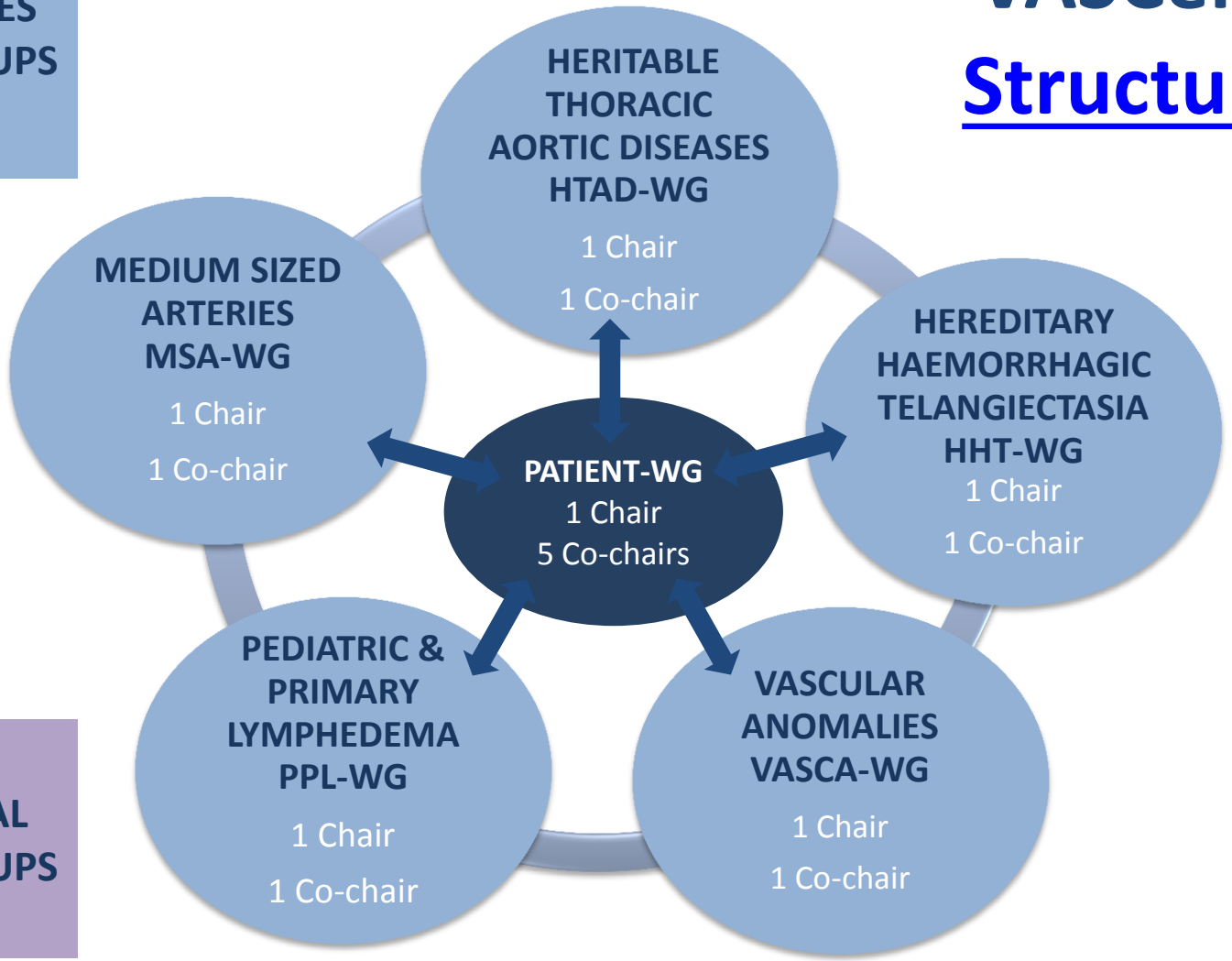
applied for ERN Membership

VASCern Governance



VASCern Structure

5 RARE DISEASES WORKING GROUPS (RDWG)



5 TRANSVERSAL WORKING GROUPS

Communication
1 Chair
1 Co-chair

eHealth
1 Chair
1 Co-chair

Ethics
1 Chair
1 Co-chair

Patient Registry
1 Chair
1 Co-chair

Training & Education
1 Chair
1 Co-chair

PATIENT-WG

Members

Patient-WG

HHT

Riet ALAVERDY, De Hart&Vaatgroep
Luisa BOTELLA, Asociación HHT España, **EPAG**
Caz COXALL, HHT UK
Claudia CROCIONE, HHT Europe, **Co-chair**
Paolo FEDERICI, Associazione Fondazione Italiana HHT 'Onilde Carini', EPAG & Patient-WG Chair
Anne GOUSTILLE, AMRO, France
Christina GRABOWSKI, Morbus Osler, Germany, **EPAG**
Diana LAWSON & Matthew FLETCHER, Telangiectasia Self Help Group, UK

HTAD

Valentina FAVALLI, MAGICA ONLUS, Italy, **Co-chair**
Maria Carla FAVINI, JPETER Marfan, Italy
Patrice TOUBOULIE, MARFANS, France, **EPAG**

MSA

Juergen GRUNERT, Vorsitzender, Deutsche Ehlers-Danlos-Initiative e.V., **EPAG & Co-chair (tbc)**
Romeo PENZO, AISED, Ehlers-Danlos

PPL

Representative names tbc

VASCA

Petra BORGARDS and Elisabeth HUHN, GERVAS, Germany
Anne-Marie MONAMI, VASCAPA
Rafaella RESTAINO, Fondazione Alessandra Bisceglia W ALE Onlus, Italy, **EPAG**
Caroline VAN DEN BOSCH & Maria JONGMA, HEVAS, NT, **Co-chair**
Ange VAN DER VELDEN, LGD Alliance Nederland, LGD Alliance Europe

Hereditary Haemorrhagic Telegiectasia HHT-WG

Rare Diseases	HHT - Hereditary Haemorrhagic Telangiectasia	
8 HCP Members HHT-WG	DE, Essen, GEISTHOFF Urban DK, Odense, KJELDSEN Anette **FR, Lyon, DUPUIS-GIROD Sophie, Co-chair** **IT, Crema, BUSCARINI Elisabetta, Deputy Co-chair** **IT, CROCIONE Claudia, Patient rep** IT, Pavia, PAGELLA Fabio IT, Bari, SABBA Carlo NT, Utrecht, MAGER Hans-Jurgen **UK, London, SHOVLIN Claire, Chair**	**Centers cooperating** ***(ongoing development)*** SP, BOTELLA Luisa

Heritable Thoracic Aortic Diseases
HTAD-WG

Rare Diseases	Marfan Syndrome type 1 and 2, Loeys Dietz Syndromes 1-6, Aneurysm Osteoarthitis Syndrome, Arterial tortuosity syndrome, Multisystemic Smooth Muscle Cell Dysplasia syndrome, Familial thoracic Aortic Aneurysms Dissections (FTAA(D)) with mutations in FBN1, TGFB2, TGFB3, SMAD2, SMAD3, TGFBR1, TGFBR2, ACTA2, MYH11, MYLK, PRKG1, FOXE3, MAT2A, MFAP5, Familial Aortic Aneurysms Dissections (FAAD), familial forms of bicuspid aortic valve with aortopathy, FBLN4 related cutis laxa, filaminopathies

13 HCP Members

HTAD-WG

BE, Ghent, DE BACKER Julie, Chair
BE, Antwerpen, LOEYS Bart
DE, Hamburg, DEBUS Sebastian
FR, Paris, JONDEAU Guillaume, Co-chair
HU, Budapest, SZABOLCS Zoltan
IT, Pavia, ARBUSTINI Eloisa
IT, FAVALLI Valentina, Patient rep
IT, Firenze, PEPE Guglielmina
IT, Milan, PINI Alessandro
NT, Amsterdam, GROENINK Maarten
NT, Radboudumc, Marlies KEMPERS
NT, Rotterdam, Ingrid VAN DER LAAR
SW, Stockholm, BJORCK Erik
UK, London, ROBERT Leema

Centers cooperating
(ongoing development)
NT, Groningen, DULFERE, Eelco
SP, Barcelona, EVANGELISTA Arturo
NT, Leiden, HILHORST Yvonne
RO, Bucharest, JURCUT Ruxandra

Medium Sized Arteries
MSA-WG

Rare Diseases	Vascular Ehlers Danlos Syndrome *To be expanded to: Takayasu disease, Thromboarteritiis obliterans (also called Buerger arteritis), arterial fibromuscular dysplasia*	
6 HCP Members MSA-WG	BE, Ghent, DE BACKER Julie BE, Antwerpen, LOEYS Bart **FR, Paris, JEUNEMAITRE Xavier, Co-chair** IT, Pavia, ARBUSTINI Eloisa IT, Milan, PINI Alessandro **UK, London, ROBERT Leema, Chair**	**Centers cooperating *(ongoing development)*** BE, Brussels, PERSU Alexandre

Pediatric and Primary Lymphedema PPL-WG

Rare Diseases	Lymphedema; Congenital Lymphedema: Milroy syndrome; Late onset lymphedema: Meige syndrome, Lymphedema distichiasis syndrome, Emberger syndrome; Lymphedema with systemic involvement: Hennekam syndrome, PIEZO1 related lymphatic dysplasia, Generalised lymphatic dysplasia, Multi-systemic lymphedema with systemic involvement; Syndromes associated with lymphedema: Noonan/CFC syndrome (RASOpathies), Turner syndrome, 22q13 microdeletion, Microcephaly with or without Chorioretinopathy, Lymphedema and Mental Retardation

8 HCP Members PPL-WG	BE, Mechelen, GIACOLONE Guido BE, Leuven, THOMIS Sarah DE, Freiburg, ROSSLER Jochen FI, Helsinki, SUOMINEN Sinikka FR, Paris, VIGNES Stephane **NT, Drachten, DAMSTRA Robert, Chair** UK, Derby, KEELEY Vaughan **UK, London, MANSOUR Sahar, Co-chair**	**Centers cooperating** ***(ongoing development)*** DE, Hinterzarten, FOLDI Etelka FR, Montpellier, QUERE Isabelle

Vascular Anomalies
VASCA-WG

Rare Diseases	venous malformation, cutaneo-mucosal venous malformation, Blue Rubber Bleb Nevus syndrome, lymphatic malformation, capillary malformation, arteriovenous malformation, diffuse capillary malformation with hypertrophy, capillary malformation-arteriovenous malformation , capillary-venous malformation , Parkes-Weber syndrome , Sturge-Weber syndrome , glomuvenous malformation, capillaro-lymphatic-venous malformation, Maffucci syndrome , CLOVES syndrome, Proteus syndrome , Macrocephaly-capillary malformation, Cutis Marmorata Telangiectatica Congenital, PTEN hamartoma tumor syndrome , cerebral cavernous malformation with or without hyperkeratotic cutaneous capillary-venous malformations, verrucous venous malformation , hereditary haemorrhagic telangiectasias , generalized lymphatic anomaly , Gorham-Stout syndrome , infantile hemangioma , rapidly involuting congenital hemangioma , non-involuting congenital hemangioma, etc.	
7 HCP Members VASCA-WG	**BE, Brussels, Laurence BOON & VIKKULA Miikka, Chair** FI, Helsinki, SALMINEN Päivi DE, Freiburg, ROSSLER Jochen IT, Rome, DIOCIAIUTI Andrea IR, Dublin, IRVINE Alan **NT, Nijmegen, SCHULTZEKOHL Leo, Co-chair** **NT, VAN DEN BOSCH Caroline, Patient rep** SW, Stockholm, GHAFFARPOUR Nader	**Centers cooperating *(ongoing development)*** SP, Barcelona, BASELGA Eulalia FR, Caen, DOMPMARTIN Anne FR, Montpellier, QUERE Isabelle IT, Milan, VAGHI Massimo

Communication WG (COM-WG)

Members	BE, Ghent, DE BACKER Julie (team member: DE HOSSON Michèle)
COM-WG	FR, Paris, HURARD Marine
	FR, Paris, JONDEAU Guillaume
NEED A CHAIR & A CO-CHAIR	IT, EPAG, RESTAINO Raffaella
	IT, Milan, PINI Alessandro
	NT, Utrecht, MAGER Hans-Jurgen
	NT, Patient rep, VAN DER VELDEN Ange
	SP, EPAG, BOTELLA Luisa-María

eHealth WG

Members eHealth-WG **NEED A CO CHAIR**	**IT, Milan, PINI Alessandro, Chair** SP, EPAG, BOTELLA Luisa-María UK, London, SHOVLIN Claire (team member : Ben GLAMPSON)	**Center cooperating** SP, BASELGA Eulalia

Ethics WG

Members	IT, Pavia, ARBUSTINI Eloisa / FAVALLI Valentina IT, Milan, PINI Alessandro
Ethics-WG	DE, EPAG, GRABOWSKI Christina NT, Patient rep, VAN DER VELDEN Ange

NEED A CHAIR & A CO-CHAIR

Patient Registry WG

Members

PR-WG

NEED A CHAIR & A CO-CHAIR

BE, Leuven, THOMIS Sarah
DE, Hamburg, BEHRENDT Christian-Alexander
FR, Lyon, DUPUIS-GIROD Sophie
FR, Paris, JONDEAU Guillaume
FR, Paris, VIGNES Stéphane
HU, Budapest, BENKE Kalman
IR, Dublin, IRVINE Alan
IT, Patient rep, CROCIONE Claudia
IT, Milan, PINI Alessandro
NT, Radboudumc, SCHULTZE KOOL Leo
NT, Radboudumc, KEMPERS Marlies
NT, Rotterdam, VAN DE LAAR Ingrid

Centers cooperating

SP, BASELGA Eulalia
SP, Barcelona, EVANGELISTA Arturo & TEIXIDO Gisela

Training & Education WG

Members

TE-WG

NEED A CO CHAIR

DE, Freiburg, ROESSLER Jochen, Chair
BE, Ghent, DE BACKER Julie (team members: VAN HERZELE Isabelle, FRANÇOIS Katrien)
BE, Leuven, THOMIS Sarah
FR, Paris, VIGNES Stéphane
IT, Rome, DIOCIAIUTI Andrea
IT, Milan, PINI Alessandro
IT, EPAG, RESTAINO Raffaella
NT, Radboudumc, KEMPERS Marlies
NT, Utrecht, MAGER Hans-Jurgen
NT, Patient rep, VAN DER VELDEN Ange
SP, EPAG, BOTELLA Luisa-María
UK, London, SHOVLIN Claire

Contact us

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