VASCern Abbreviation List

ACTA2 Alpha-actin-2

ALK1 activin receptor like kinase 1

AOS Aneurysm-Osteoarthritis Syndrome

ATS Arterial Tortuosity Syndrome

AVF ArterioVenous Fistula

AVM ArterioVenous Malformation

AVMs arteriovenous vascular malformations

BAV Bicuspid Aortic Valve

BMI Body mass index

BRBN Blue Rubber Bleb Nevus syndrome

CAVM cerebral arteriovenous vascular malformations

CCM Cerebral Cavernous Malformation

CFC cardio-facio-cutaneous syndrome

CLM Capillary Lymphatic Malformation

CLOVES Congenital, Lipomatous, Overgrowth, Vascular Malformations, Epidermal Nevi and Spinal/Skeletal Anomalies and/or Scoliosis

CM Capillary Malformation

CM-AVM Capillary Malformation-ArterioVenous Malformation

CMDV Capillary Malformation with Dilated Veins

CMTC Cutis Marmorata Telangiectatica Congenita

CO Cardiac output

COL3A1 Collagen Type III Alpha 1

CSAL Circumferential suction assisted lipectomy

CT Computed Tomography

CT scan Computed Tomography scan

CVM Capillary Venous Malformation

DCMO Diffuse Capillary Malformation with Overgrowth

EC European Commission

EDS Ehlers-Danlos Syndrome

EDS4 / EDS IV Ehler Danlos syndrome type 4 (vascular type)

e-Health electronic Health

ELN Elastin

ENG endoglin

ENT Ear Nose and Throat

EPAG EURORDIS Patient Advocacy Group

ERN European Reference Network

ESC European Society of Cardiology

ESS Epistaxis severity score

EURORDIS Rare Diseases Europe (Patient Association)

FBLN4 Fibulin-4

FBN1 Fibrillin-1

FLNA Filamin A

FTAAD Familial Thoracic Aortic Aneurysm & Dissection

GLA Generalized Lymphatic Anomaly

GLD Generalized lymphatic dysplasia

GSD Gorham-Stout Disease

GVM GlomuVenous Malformation

HAIR Haemorrhage adjusted iron requirement

HAVM hepatic arteriovenous vascular malformations

HCCVM Hyperkeratotic Cutaneous Capillary-Venous Malformation

HECOVAN Heamangioma and COgenital Vascular Anomalies Nijmegen

HEVAS Patient organisation for heamangioma and vascular malformations

HHT Hereditary Haemorrhagic Telangiectasia

HHT-WG Hereditary Haemorrhagic Telangiectasia Working Group

HOCF high output cardiac failure

HTAD Heritable Thoracic Aortic Diseases

HTAD-WG Heritable Thoracic Aortic Diseases Working Group

ICF International Classification of functioning, disability and health

ICT Information and Communication Technologies

ILF International Lymphedema Framework

ISSVA International Society for the Study of Vascular Anomalies

KHE Kaposiform Hemangioendothelioma

KTS Klippel-Trenauany syndrome

LDS Loeys-Dietz Syndrome

LM Lymphatic Malformation

LOX lysyl oxidase

LVM LymphaticoVenous Malformation

MCLMR Microcephaly with or without Chorioretinopathy, Lymphedema and Mental Retardation

M-CM Macrocephaly - Capillary Malformation syndrome

MFAP5 Microfibrillar associated protein 5

MFS Marfan Syndrome

m-Health mobile Health

MR lymphography Magnetic resonance Lymphography

MRI Magnetic Resonance Imaging

MS multiple sclerosis

MSA-WG Medium Sized Arteries Working Group

MSSMDS Multisystemic Smooth Muscle Cell Dysfunction syndrome

MSVM Multifocal Sporadic Venous Malformation

MYH11 myosin heavy chain kinase

MYLK myosin light chain kinase

NGS next-generation sequencing

NIAZ Het Nederlands Instituut voor Accreditatie in de Zorg

NICH Non Involuting Congenital Hemangioma

NLP Natural Language Processing

OLT orthotopic liver transplant

OP operation

PAH Pulmonary arterial hypertension (the preferred name for PPH)

Patient-WG Patient Working Group

PAVM pulmonary arteriovenous vascular malformations

PC Personal Computer

PDA persistent ductus arteriosus

PET Positron Emission Tomography

PG Pyogenic Granuloma

PHACES Posterior fossa malformations–Hemangiomas–Arterial anomalies–Cardiac defects–Eye abnormalities–Sternal cleft and supraumbilical raphe syndrome

PHTS Pten Hamartoma Tumor Syndrome

PHTS PTEN hamartoma tumor syndrome

PPH primary pulmonary hypertension

PPL Pediatric and primary lymphedema

PPL-WG Pediatric and Primary Lymphedema Working Group

PRKG1 protein kinase, cGMP-dependent, type I

PROM Patient Reported Outcome Measures

PROS PIK3CA Related Overgrowth Syndrome

PW Password

PWS Parkes-Weber syndrome

PWS Port-Wine Stain

QoL Quality of life

RDWG Rare Diseases Working Group

RICH Rapidly Involuting Congenital Hemangioma

ROW Rendu Osler Weber

SMAD3 mothers against decapentaplegic homolog 3

SWS Sturge-Weber Syndrome

TA Tufted Angioma

TAAD thoracic aortic aneurysm&dissection

TGFBR transforming growth factor beta receptor

TGFβ transforming growth factor beta

UMLS Universal Medical Language System

VAC Vascular Anomaly Center

VASCAPA VASCular Anomaly Patient Association

VASCA-WG Vascular Anomalies Working Group

VASCern ERN Rare Multisystemic Vascular Diseases

vEDS vascular Ehlers-Danlos syndrome

VM Venous Malformation

VMCM Venous Malformation, Cutaneous and Mucosal

WG Working Group