



Directory of ePAG [European Patient Advocacy Groups] representatives

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European Patient Advocacy Groups (ePAGs) are patient forums comprised by ePAG Patient Advocates designated by Patient Organisations wishing to engage in a specific European Reference Network (ERN). Each European Reference Network has one European Patient Advocacy Group.

Rare disease Patient Organisations, EURORDIS members and non-members established in Europe, may endorse ePAG Patient Advocates to be actively involved in the activities and governance structure of a European Reference Network. Each of the 24 ePAGs coordinates the recruitment of new ePAG Patient Advocates in collaboration with the ERN Network Coordinator. The application process and eligibility criteria is detailed in the **ePAG Constitution and Rules of Procedure**.

- **Rare Bone ePAG**
- **Inês Alves**, Fundación ALPE Acondroplasia
- **Claudia Finis**, Deutsche Gesellschaft Für Osteogenesis Imperfecta (Glasknochen) Betroffene E.V.
- **Elisabeth Martin**, Association Ollier-Maffucci Europe
- **Tenna Toft Olesen**, XLH Patientenforeningen
- **Rebecca Tvedt Skarberg**, Osteogenesis Imperfecta Federation Europe

- **Rare Cancer ePAG**

- **Catherine Bouvier**, NET patient Foundation UK
- **Laura Abate Daga**, Associazione Tumori Torarici Rari Onlus
- **Iain Galloway**, MPNE Ocular/Rare
- **Emma Kinloch**, Adenoid Cystic Carcinoma
- **Teodora Kolarova**, International Neuroendocrine Cancer Alliance (INCA)
- **Estelle Lecointe**, ASSOCIATION FRANÇAISE DES PATIENTS DU GIST - ENSEMBLE CONTRE LE GIST
- **Kathy Oliver**, International Brain Tumour Alliance (IBTA)
- **Timur Ohloff**, German Foundation for Young Adults with Cancer
- **Roberto Persio**, Associazione Italiana Laryngectomizzati (AILAR)
- **Eva-Maria Strömsholm**, European Network of Gynaecological Cancer Advocacy Groups
- **Judith Taylor**, Thyroid Cancer Alliance
- **Vassiliki Fotaki**, Digestive Cancers Europe

- **Markus Wartenberg** , Das Lebenshaus e.V. - Die Organisation für Patienten mit seltenen Soliden Tumoren:GIST/Sarkome/Nierenkrebs
- **Petya Zyumbileva**, Melanom Info Deutschland

• **Rare connective tissue and musculoskeletal diseases ePAG**

- **Silvia Aguilera**, Asociación Española Síndrome Antifosfolípídico
- **Jeanette Andersen**, Lupus Europe
- **Coralie Bouillot**, Association Française du Gougerot-Sjögren
- **Paolo Corti**, Relapsing Polychondritis Patient Support Group
- **Alain Cornet**, Lupus Europe
- **Charissa Frank**, Vlaamse Vereniging voor Erfelijke Bindweefselaandoeningen
- **Ilaria Galetti**, Gruppo Italiano per la Lotta alla Sclerodermia ONLUS
- **Monica Holmner**, Federation of European Scleroderma Associations
- **Ana Vieira**, Liga Portuguesa contra as Doenças Reumáticas
- **Lisa Matthew**, Relapsing Polychondritis Narrative

- **Rare craniofacial anomalies and ENT disorders ePAG**
- **Gareth Davies**, European Cleft Organisation
- **Michel Francois**, Association nationale pour la promotion et le developpement de la langue francaise parlee completee
- **Elisa Kilpiäinen**, Finish Cleft Lip Patients Association
- **Barbara Lieuwen**, Voorzitter Laposa
- **Thomas Luck**, Netzrverk Goldenhar-Syndrom und Ohrmuscheldysplasie e.V.
- **Anne-Sophie Mercey-Jarosz**, Association Mille et une têtes
- **Sandra Mösche**, Elterninitiative Apert-Syndrom und verwandte Fehlbildungen e. V
- **Philippe Pakter**, Stichting Pierre Robin Europe - Pierre Robin Europe Foundation
- **Sara Perez**, Asociación Nacional Síndrome de Joubert
- **Markus Richter**, Elterninitiative Apert-Syndrom Und Verwandte Fehlbildungen E. V.

- **Karen Wilkinson-Bel**, Headlines Craniofacial Support

- **Rare endocrine diseases ePAG**

- **Beate Bartés**, Vivre sans Thyroïde
- **Johan Beun**, Bijniervereniging NVACP
- **Petra Bruegmann**, European MEN Alliance
- **Manuela Brösamle**, AGS- Eltern- und Patienteninitiative e.V.
- **Patricia Carl**, Bundesverband Kleinwüchsige Menschen und ihre Familien e.V.
- **Valeria Corradin**, Associazione Italiana Lipodistrofie
- **Johan de Graaf**, Nederlandse Hypofyse Stichting (Dutch Pituitary Foundation)
- **Nathalie Ferard**, Association Grandir
- **Elisabetta Freo**, L'Associazione Famiglie di Soggetti con Deficit dell'Ormone della Crescita ed altre Patologie
- **Jette Kristensen**, Addison Foreningen i Danmark
- **Martha Kirchhoff**, Phosphatdiabetes e. V.

- **Alessandro Lazzerini**, Association of Congenital Adrenal Hyperplasia
- **Berit Otterlei**, Norwegian organisation for Prader Willis syndrome
- **Arlene Smyth**, Turner Syndrome Support Society
- **Diana Vitali**, SOD Italia - Associazione Italiana Displasia Setto Ottica e Ipoplasia del Nervo Ottico

- **Rare eye diseases ePAG**
- **Petia Stratieva**, Retina International
- **Dominique Sturz**, Usher Deafblind Forum Austria
- **Russel Wheeler**, Leber's Hereditary Optic Neuropathy Society

- **Rare gastrointestinal diseases ePAG**
- **Duccio Cavalieri**, Associazione Italiana Morbo di Hirschsprung
- **Fanny Cauvet**, European Society of Pediatric Gastroenterology Hepatology and Nutrition
- **Dirk-Jan Gloudemans**, Vereniging Ziekte Van Hirschsprung
- **Annette Lemli**, Selbsthilfeorganisation für Menschen mit Anorektalfehlbildungen
- **Frank Meijer**, PlatformCHD
- **Beverley Power**, CDH UK
- **Graham Slater**, The Federation of Esophageal Atresia and Tracheo-Esophageal Fistula Support Groups e.V.
- **Anke Widenmann Grolig**, Patienten- und Selbsthilfeorganisation für Kinder und Erwachsene mit kranker Speiseröhre

- **Rare Pediatric Cancer ePAG**

- **Luisa Basset**, Federación Española de Padres de Niños con Cáncer & Childhood Cancer International – Europe
- **Anne Goeres**, Fondatioun Kriibskrank Kanner & Childhood Cancer International – Europe
- **Lejla Kamerić**, Heart for kids with cancer in FBiH (Srce za djecu koja boluju od raka u FBiH) & Childhood Cancer International – Europe
- **Anita Kienesberger**, Austrian Childhood Cancer Organization & Childhood Cancer International – Europe

- **Rare hematological diseases ePAG**
- **Dag Erling Stakvik**, European Federation of Associations of Patients with Haemochromatosis
- **Jan Geissler**, Leukemia Patient Advocates Foundation
- **Angelo Loris Brunetta**, Associazione Ligure Talassemici Onlus
- **Ananda Plate**, Myeloma Patients Europe
- **Maria Piggin**, PNH Support UK
- **Sophie Wintrich**, MDS UK Patient Support Group
- **Baiba Ziemele**, Latvia Hemophilia Society

- **Rare hepatic diseases ePAG**
- **Michael Donaubauer**, Deutsche Leberhilfe
- **Anna Gambarotto**, Associazione Malattie Autoimmuni del Fegato
- **Vittorio Gnutti**, Associazione Malattie Autoimmuni del Fegato
- **Tess Harris**, PKD UK
- **Uwe Korst**, PKD Familiäre Zystennieren e.V.
- **Angela Leburgue**, Association pour la Lutte contre les maladies Inflammatoires du Foie et des voies biliaires
- **Ernst Leitgeb**, Hepatitis Aid Austria
- **Lone McColaugh**, Leverforeningen
- **Biljana Mirceska**, NGO SLAP - Save Liver Association of Patients
- **Caroline Roatta**, Association Bernard Pépin pour la Maladie de Wilson

- **Camille Thron-Charles**, AMFE Association Maladies FOIE
- **Bert Tomsin**, Vlaamse PBC, PSC patiëntenvereniging Vzw
- **Martine Wallsmley**, PSC Support, UK
- **Jose Willemse**, Nederlandse Leverpatienten Vereniging

- **Rare hereditary metabolic disorders ePAG***
- **Renza Barbon**, UNIAMO
- **Lut de Baere**, BOKS
- **Julia Boonak**, CGD UK
- **Beatruice Casado Verrrier**, Familial GA₁
- **Tanaya Collin**, European Gaucher Alliance
- **Dorinda Dams Silva**, APCDG-RMD (CDG)
- **Hanka Dekker**, VKS, The Netherlands
- **Marie Devaux**, Phenylcetonurie, France
- **Covadonge Diaz Martinez**, Asociación por la vida con GLUT-1
- **Luigi Distefano**, Association Française Niemann Pick
- **Antje Enekwe**, SLO Deutschland

- **Alan Finglas**, MSD Action Foundation
- **Anne Hugon**, Association Francophone des Glycogénoses
- **Marija Joldic**, Association For Help And Support People With Hunter Syndrome in Serbia
- **Anne Gregoriades**, VML
- **Anne Kalweit**, SLO Deutschland
- **Enrique Landilo Contreras Pulido**, GSD Spain
- **Anne Grethe Lauridson**, European Gaucher Alliance
- **Daniel Lewi**, Cure & Action for Tay-Sachs Foundation
- **Nuno Marques**, Rarissimas (LSD)
- **Davidonis Martynas**, FIN (Fabry)
- **Toni Mathieson**, Niemann-Pick UK
- **Anna Merilouto**, Fabry International Network
- **Alexander Niehaus**, Asociación por la vida con GLUT-1

- **Laura Rossi Brunori**, AIG (Gaucher)
- **Thomas Schaller**, Pompe Deutschland e.V.
- **Silvia Sestini**, Associazione Italiana Malati di Alcaptonuria
- **Stefania Tobaldini**, Onlus Italy
- **Fernanda Torquati**, Gaucher, Italy
- **Erica Van der Mheen**, Fabry Support & Informatie Groep Nederland
- **Guiliana Valerio**, Associazione Italiana Sostegno Malattie Metaboliche Ereditarie Onlus
- **Paula Videira**, APCDG -NMR (CDG)
- **Leona Wagner**, DSAKU

**This list is incomplete and will be updated in due course*

- **Rare immunological & auto inflammatory diseases ePAG**
- **Zoi Anastasia**, Vasculitis UK
- **Eugenia Durante**, Associazione Pazienti della Sindrome di Churg Strauss
- **Andrea Gressani**, Associazione per le immunodeficienze primitive Onlus
- **Jaana Grönholm**, Suomen Vaskuliittiyhdistys Ry
- **Saara Kiema**, International Patient Organization for Primary Immunodeficiencies
- **Diana Marinello**, Associazione Italiana Sindrome e Malattia di Behcet
- **Paul Morgan**, FMF & AID
- **Julie Power**, Vasculitis Ireland
- **Rachel Rimmer**, RACC – UK
- **Stephanie Skeffington**, Irish Children’s Arthritis Network
- **Mailis Suhonen**, Suomen Vaskuliittiyhdistys Ry

- **Francesca Romana Torracca**, Associazione Pazienti della Sindrome di Churg Strauss
- **Malena Vetterli**, FMF & AID
- **Carlota Villar**, Barcelona PID Foundation

- **Rare malformations / developmental anomalies/and rare intellectual disabilities ePAG**

- **Papatya Alkan**, International Federation for Spina Bifida and Hydrocephalus
- **Dorica Dan**, Romanian National Alliance for Rare Diseases
- **Sandrine Daugy**, Génération 22
- **Ioel Detton**, Association Noonan
- **Tomasz Grybek**, Fundacja Bohatera Borysa
- **Carole Herman**, Amis de ADNP France
- **Gerritjan Koekkoek**, Cornelia De Lange Syndrome World Federation
- **Pietro Marinelli**, ASSOCIAZIONE SMITH-MAGENIS ASM17 ITALIA ONLUS
- **Gabor Pogany**, FEWS - Federation of European Williams Syndrome
- **Sylvia Roozen**, International Federation for Spina Bifida and Hydrocephalus

- **Sue Routledge**, Pitt Hopkins UK
- **Annalisa Scopinaro**, APWItalia
- **Katarzyna Świczowska**, Polish Association for Persons with Intellectual Disability
- **Gianluca Vizza**, Associazione Italiana Sindrome Di Pitt-Hopkins Insieme Di Più - Onlus

- **Rare multi-systemic vascular diseases ePAG**
- **Romain Alderweireldt**, Association Belge du Syndrome de Marfan ASBL
- **Margit Aschenbrenner**, Marfan Initiative Österreich
- **Maria Barea**, Vascular Anomaly Patient Association
- **Rita Blom**, Hart&Vaatgroep
- **Petra Bogards**, Bundesverband Angeborene Gefäßfehlbildungen e.V.
- **Luisa Botella**, Asociación HHT España
- **Claudia Crocione**, Associazione Italiana Teleangectasia Emorragica Italiana - HHT ONLUS
- **Elena de Moya Rubio**, MARFAN HILFE DEUTSCHLAND E.V.
- **Karen Druckman**, HTT Swiss
- **Paolo Federici**, Associazione Fondazione Italiana HHT "Onilde Carini"
- **Charissa Frank**, Vlaamse Vereniging voor Erfelijke Bindweefselaandoeningen
- **Christina Grabowski**, HHT Europe
- **Juergen Grunert**, Deutsche Ehlers-Danlos Initiative e. V

- **Pernille Henriksen**, Dansk Lymfødem Forening
- **Lex van der Heijden**, Cutis Marmorata Telangiectatica Congenita and other Vascular Malformations
- **Eline Hoogstra**, Nederlands Netwerk voor Lymfoedeem & Lipoedeem (NLNet)
- **Manuela Lourenço Marques**, National Association of Sufferers of Lymphatic Disorders Portugal **Lise Murphy**, Svenska Marfanföreningen
- **Diana Maas**, Contactgroep Marfan Nederland
- **Elena Matta**, Lymphido ONLUS
- **Carina Mainka**, KIF11 Kids e.V.
- **Carmen Quirós**, SIMA Asociación de afectados Síndrome de Marfan
- **Sara Rosén Larsson**, Swedish Association of Chronic Oedema
- **Silvie Slívová**, Avminority
- **Françoise Steinbach**, Association Marfans
- **Caroline Van Den Bosch**, HEVAS
- **Aaike van Oord**, LGD Alliance Europe



- Dara Woods, HHT Ireland

- **Rare neurological diseases ePAG**
 - **Astri Arnesen**, European Huntington Association
 - **Monika Benson**, Dystonia Europe
 - **Nataliya Elenkova Grigorova**, Bulgarian Huntington Association
 - **Mary Kearney**, Friedreich's Ataxia Research Alliance Ireland (FARA)
 - **Lori Renna Linton**, Euro-HSP
 - **Lubomir Mazouch**, Spolek pro Atypické Parkinsonské syndromy
 - **Tobias Mentzel**, Association Européenne Contre Les Leucodystrophies
 - **Marek Parowicz**, Association AHC18+ e. V.

- **Rare neuromuscular diseases ePAG**

- **Bobby Ancil**, Muscular Dystrophy UK
- **Dimitrios Athanasiou**, MDA Hellas/UPPMD
- **Patrizia Blomkwist Markens**, Spierziekten Nederland - Dutch Patient Society of Neuromuscular Diseases
- **Joaquim Brites**, Associacao Portuguesa de Neuromusculares
- **Ria Broekgaarden**, Dutch Patient Society of Neuromuscular Diseases
- **Nic Bungay**, Muscular Dystrophy UK
- **Fernanda de Angelis**, Duchenne Parent Project Italy
- **Ingrid de Groot**, Spierziekten Nederland - Dutch Patient Society of Neuromuscular Diseases
- **Mencía de Lemus Belmonte**, Fundame Spain/SMA Europe
- **Emma Del Rey**, French Association for Mitochondrial Diseases
- **Marguerite Friconneau**, AFM-Téléthon
- **Rosanna Fodera**, MITOCON ONLUS
- **Patrizia Garzena**, CIDP Italia Onlus

- **Jérémie Gautreau**, French Association against Peripheral Neuropathies
- **Filippo Genovese**, ACMT-Rete
- **Madelon Kroneman**, Spierziekten Nederland
- **François Lamy**, AFM-Téléthon
- **San Jose Leticia**, ASEM Cataluna
- **Massimo Marra**, CIDP Italia Onlus
- **Alexandre Mejat**, AFM-Téléthon
- **Marisol Montolio**, Duchenne Parent Project Spain
- **Michela Onali**, Gli Equilibristi-HIBM
- **Marie-Christine Ouillade**, AFM-Téléthon
- **Françoise Pelcot**, French Association Against Amyloidosis
- **Alejandra Pereda**, Duchenne Parent Project Spain
- **Francisco Javier Pérez-Martinez**, Fundación Ana Carolina Díez Mahou/ AEPMI / Federación
- **Jean-Philippe Plançon**, French Association against Peripheral Neuropathies
- **Evy Reviere**, ALS Liga Belgium
- **Jacques Salama**, Former General Secretary of the Myology Institute

- **Sandrine Segovia-Kueny**, AFM-Téléthon
- **Inge Schwersenz**, Deutsche Gesellschaft für Muskelkranke
- **David Stephenson**, Muscular Dystrophy UK
- **Daniel Tanesse**, Charcot Marie Tooth-France/European CMT Federation
- **Isabela Tudorache**, PPMD
- **Diana van der Meij-Kim**, FSHD EU
- **Judit Varadine Csapo**, Angyalszarnyak Hungarian Muscle Dystrophy Association
- **Dominic Wells**, Muscular Dystrophy UK
- **Gerard Wellenberg**, Myotonic Dystrophy

- **Rare renal diseases ePAG**
- **David Attar**, Primäre Hyperoxalurie Selbsthilfegruppe E.V
- **Manuel Arellano**, Fundación Renal Alcer
- **Alena Blaß**, aHUS
- **Marjolein Bos**, VKS-Cystinose Groep
- **Antonio Cabrera Cantero**, Hypomagnesemia
- **Suzanna Carvajal Arjona**, Hipofam
- **Flavia Galetti**, Associazione Italiana Rene Policistico Onlus
- **Susie Gear**, Alport UK
- **Tess Harris**, Ciliopathy Alliance
- **Terry Hoey**, The Cavan Tommy Hoey Trust
- **Tonia Hymers**, Bardet Bidle Syndrome UK
- **Juan Carlos Julián Mauro**, Spanish Kidney Patients Federation

- **Uwe Korst**, PKD Familiäre Zystenniere e. V.
- **Francisco Monfort**, Ashua - Atypical Hemolytic Uremic Syndrome (Ahus)
- **Johanna Rohlfig**, Nephie e.V. - Selbsthilfe nephrotisches Syndrom
- **Michel Schenkel**, FEDERG - Federation of European Associations of Patients affected by Renal Diseases
- **Claudia Sproedt**, Cystinose Selbsthilfe e.V.
- **Karlheinz Steinecker**, Association pour l'information et la recherche sur les Maladies Rénales Génétiques
- **Marjolein Storm**, Nierpatienten Vereniging Nederland
- **Isabelle Tostivint**, L'Association LUNNE
- **Evy van Kempen**, Nierpatiënten Vereniging Nederland (Dutch Kidney Patients Association)
- **Marieke van Meel**, NephcEurope
- **Heidi Zealey**, Alport UK

- **Rare Skin Disorders ePAG**
- **Marie-Claude Boiteux**, Cutis Laxa Internationale
- **Laurence Gallu**, Association Pemphigus – Pemphigoïdes France
- **Antoine Gliksohn**, Genespoir: Association Française des Albinismes
- **Ulrike Holzer**, Selbsthilfegruppe Ektodermale Dysplasie e.V.
- **Ingrid Jageneau**, Debra Belgium vzw
- **Diana Perry**, ED Society
- **Núria Tarrats Font**, Asociación de Epidermolisis Bullosa de España
- **Karin Veldman**, Vereniging voor Ichthyosis Netwerken
- **Bente Villumsen**, Hidrosadenitis-Denmark
- **Giulia Volpato**, p63 EEC Syndrome International network word communication
- **Anna Wiegandt**, Selbsthilfe Ichthyose e.V.

- **Marjolein van Kessel**, Naevus Global
- **Lex van der Heijden**, Cutis Marmorata Telangiectatica Congenita and other Vascular Malformations

- **Rare urogenital diseases ePAG**
- **Dalia Aminoff**, AIMAR
- **Rita Serena Bartezzati**, AICI Associazione Italiana Cistite Interstiziale
- **Robert Cornes**, Orchid UK
- **Claire Harkin**, Klinefelter's Syndrome Association
- **Christiann Groen**, Dutch Bladder Extrophy
- **Nicole Schwarzer**, Selbsthilfeorganisation für Menschen mit Anorektalfehlbildungen
- **Kenneth Manzie**, Orchid UK
- **John Osborne**, Orchid UK

- **Rare Pulmonary ePAG**

- **Marta Almagro**, European Lung Foundation
- **Edwin Brekelmans**, Alpha 1 Global
- **Jeannette Boyd**, European Lung Foundation
- **Alessandro Carcano**, Associazione Italiana Per La Sindrome Da Ipoventilazione Centrale Congenita
- **Hilde de Keyser**, Association Muco Vereniging
- **Fabio Ferrini**, Associazione Nazionale Alfa₁-At
- **Liam Galvin**, Irish Lung Fibrosis Association
- **Kate Hill**, June Hancock Mesothelioma Research Fund
- **Johann Hochreiter**, Lungenfibrose Forum Austria
- **Dagmar Kauschka**, ERWACHSENEN-HISTIOZYTÖSE X E.V.
- **Natalia Maeva**, The Bulgarian Society of Patients with Pulmonary Hypertension
- **Filippo Martone**, Amici Contro la Sarcoidosi Italia ONLUS

- **Luc Matthysen**, Association de patients souffrant d'hypertension artérielle pulmonaire en Belgique
- **Gergely Meszaros**, Pulmonary Hypertension Association Europe
- **Karen O'Hara**, Alpha 1 Global
- **Stefano Pavanello**, Unione Trapiantati Polmone Di Padova
- **Pippa Powell**, European Lung Foundation
- **Marjo Poulissen**, Longfonds
- **Bernd Quadder**, Deutsche Sarkoidose Vereinigung Gemeinnütziger e.V.
- **Bernhard Rindlisbacher**, KARTAGENER SYNDROM & PRIMÄRE CILIÄRE DYSKINESIE(E.V.)
- **Bernd Stachetzki**, Sarkoidose Netzwerk
- **Stefano Guerini**, ASSOCIAZIONE NAZIONALE ALFA₁-AT
- **Anke Widenmann-Grolig**, The Federation of Esophageal Atresia and Tracheo-Esophageal Fistula Support Groups e.V.

• **Rare Genetic Tumour Risk Syndromes ePAG**

- **Claudio Ales**, Associazione Italiana per la lotta alle PHTS
- **João de Sousa e Silva**, NF Patients United
- **Tamara Hussong Milagre**, Evita (Portuguese Association of carriers of genetic mutations related to Hereditary Cancer)
- **Rita Magenheim**, German Li Fraumeni Association
- **Nicola Reents**, Familienhilfe Darmkrebs e.V. / Semi-Colon (German patient association for Lynch and Polyposis)
- **Claas Röhl**, NF Kinder – Verein zur Förderung der Neurofibromatoseforschung Österreich
- **Tanja Spanic**, Europa Donna Slovenia
- **Salvo Testa**, MUTAGENS

- **Rare Epilepsies ePAG**

- **Jose Angela Aibar**, Fundación Síndrome de Dravet
- **Irena Bibic**, Dravet syndrome Croatia
- **Isabella Brambilla**, Dravet Italia Onlus
- **Ben Clay**, SCN8A UK & Ireland
- **Monica Lucente**, Associazione Italiana Glut1
- **Barbara Nicol**, Purple Day Spain
- **Emma Nott**, Hope For Hypothalamic Hamartomas UK
- **Carol Anne Partridge**, CDKL5
- **Rosaria Vavassori**, Italian patient organization for AHC, A.I.S.EA Onlus
- **Allison Watson**, Ring 20 UK

- **Transplantation in Children ePAG***
- **Matilde Correia**, Associação Portuguesa de Insuficientes Renais
- **Nana Gomex Mayoral**, HEPA
- **Stefano Pavanello**, Unione Trapiantati Polmone di Padova
- **Alba Santos**, NUPA
- **Alison Taylor**, Children's Liver Disease Foundation Diverse Disease
- **Conchita Velázquez-Gaztelu**, NUPA
- **Kristina Zaveckiene**, Lithuanian Children's Cancer Association

**This list is incomplete and will be updated in due course*

- **Rare and Low Prevalence Complex Diseases of the Heart ePAG**
- **Ruth Biller**, ARVC-Selbsthilfe e.V
- **Edward Callus**, European Congenital Heart Disease Organisation
- **Ester Costafreda**, Asociacion SAMS
- **Steven Cox**, Cardiac Risk in the Young
- **Simone de Vergori**, ACMRC ONLUS Associazione Cardiomiopatie e Malattie Rare Connesse ONLUS
- **Katja Laine**, sydänpäivät ja -aikuiset (Finnish Association for Heart Children and Adults)
- **Simone Louisse**, Stichting Hart4Onderzoek
- **Peter Nordqvist**, Swedish Heart Foundation
- **Sophie Pierre**, Association des Maladies héréditaires du Rythme Cardiaque
- **Inge Schalkers**, Haarteraad
- **Lisbeth Vestergaard Andersen**, Danish Heart Foundation
- **Dayenne Zwaagman**, Stichting Hart4Onderzoek