1. Rare Bone ePAG

Inês Alves, Fundación ALPE Acondroplasia	**Liesbeth Siderius,** Dutch Shwachman Diamond Patient Org	**Jean Moitry**, Association de L'Osteogenese Imparfaite	**Rebecca Tvedt Skarberg,** Osteogenesis Imperfecta Federation Europe

2. Rare Cancer ePAG

Kathy Oliver, International Brain Tumour Alliance	**Isabelle Manneh-Vangramberen**, European Cancer Patient Coalition (ECPC)	**Estelle Lecointe-Artzner** Sarcoma Patients EuroNet (SPAEN)	**Markus Wartenberg** Sarcoma Patients EuroNet (SPAEN	**Teodora Kolarova** International Neuroendocrine Cancer Alliance (INCA)	**Catherine Bouvier** International Neuroendocrine Cancer Alliance (INCA) & NET Patient Foundation UK	**Jo Grey** AMEND UK	**Iain Galloway** MPNE Ocular/ Rare

3. Rare connective tissue and musculoskeletal diseases ePAG

Charissa Frank, Bindweefsel.be (Vlaamse Vereniging voor Erfelijke Bindweefselaandoeningen vzw)	**Jürgen Grunert,** Deutsche Ehlers-Danlos-Initiative e.V.	**Marianne Riviere,** Association Française du Lupus et autres Maladies Auto-Immunes (AFL +)	**Ilaria Galetti,** SOSTIENI LA RICERCA PER LA SCLEROSI SISTEMICA - SCLERODERMIA

4. Rare craniofacial anomalies and ENT (ear, nose and throat) disorders ePAG

Sara Perez, Asociación Nacional Sindrome de Joubert	**Gareth Davies**, European Cleft Organisation

5. Rare endocrine diseases ePAG

Johan de Graaf, Nederlandse Hypofyse Stichting	**Jette Kristens**	**Johan Beun,** Bijniervereniging NVACP	**Petra Bruegmann**,	**Diana Vitali**, Associazione Italiana

	en, Addison Forening en i Danmark			Netzwerks Hypophysen- und Nebennieren erkrankunge n e. V.	Displasia Setto Ottica e Ipoplasia del Nervo Ottico

6. Rare eye diseases

Christina Fasser & Avril Daly, Retina International	**Michael Längsfeld**, PRO RETINA Deutschland	**Paula Morandi**, MITOCON ONLUS	**Gaelle Jouanjan**, FRANCE & ANIRIDIA EUROPE	**Daniela Brohlburg**, PRO RETINA Deutschland	**Russel Wheeler**, Leber's Hereditary Optic Neuropathy Society

7. Rare gastrointestinal diseases

Anke Widenmann-Grolig, EAT The federation of Esophageal Atresia and Tracheo-esophageal fistula support groups e.V.		**Nicole Schwarzer**, SoMA for Hirschsprung Disease and Anorectal Malformation	**Bailly Villette,** LEONORE	**Graham Slater**, **JoAnne Fruithof Frederic Armandm**, The Federation of Esophageal Atresia and Tracheo-Esophageal Fistula
Fanny Cauvet, Association APEHDia	**Mrs. Antje Feldtmann-Korn,** KISE	**Benoit Decavele,** La Vie par un Fil		**Beverley Power,** CDH UK

8. Rare Paediatric Cancer ePAG

Anita Kienesberger, Stephanie Shremmer Austrian Childhood Cancer Organization	**Luisa Basset**, Federación Española de Padres de Niños con Cáncer	**Lejla Kamerić**, Heart for kids with cancer in FBiH (Srce za djecu koja boluju od raka u FBiH)

9. Rare haematological diseases ePAG

Amanda Bok, European Haemophilia Consortium	**Jan Geissler**, Leukemia Patient Advocates Foundation	**Sophie Wintrich**, MDS UK Patient Support Group	**Angelo Loris Brunetta,** Associazione Ligure Thalassemici Onlus	**Ananda Plate**, Myeloma Patients Europe	**Pierre Aumont,** Association de Soutien et d'Information à la Leucémie Lymphoïde

					Chronique et la maladie de Waldenström

10 Rare hepatic diseases ePAG

Marleen Kaatee, PSC Patients Europe	**Robert Dixon & Robert Mitchell Thain,** PBC Foundation	**Barbara Borik,** Deutsche Morbus Crohn / Colitis ulcerosa Vereinigung (DCCV) e.V.	**José Willemse**, Dutch Liver Patients Association (Nederlandse Leverpatiënten Vereniging)	**Lone McColaugh,** Leverforeningen	**Alison Taylor**, Children's Liver Disease Foundation	**Biljana Mirceska** & **Milan Mishkovikj** NGO SLAP Save Liver Association Patients, Pr	**Frank Willersinn,** Alpha-1 Plus Belgium & **Sandrine Lefrancois**, Alpha 1 France

11 Rare hereditary metabolic disorders ePAG

Renza Barbon Galluppi, Associazione Italiana Sostegno Malattie Metaboliche Ereditarie Onlus	**Lut De Baere**, Belgische Organisatie voor Kinderen en Volwassenen met een Stofwisselingsziekte	**Vanessa Dos Reis Ferreira**, Portuguese Association for CDG	**Anne Hugon**, Association Francophone des Glycogenoses	**Anne-Sophie Lapointe**, Vaincre les Maladies Lysosomales	**Cinzia Arbellino**, MITOCON ONLUS	**Claudia Sproedt**, Cystinose-Selbsthilfe e.V.

12 Rare immunological & auto inflammatory diseases ePAG

Diana Marinello, Associazione Italiana Sindrome e Malattia di Behcet	**John Mills**, Vasculitis UK	**Peter Verhoeven**, Vasculitis Stichting	**Richard West**, Behcets International	**Malena Vetterli,** FMF & AID

13 Rare malformations / developmental anomalies/and rare intellectual disabilities ePAG

Tobias Arndt, European Dysmelia Reference Information Centre	**Dorica Dan**, Romanian Prader Willi Association	**Gabor Pogany**, Hungarian Williams Syndrome Association	**Yvonne Milne**, Rett Syndrome Europe	**Ammi Andersson**, International Federation Spina Bifida & Hydrocephalus	**Sue Routledge,** Pitt Hopkins UK	**Luis Quaresma,** Portuguese Spina Bifida & Hydrocephalus Association

14 Rare multi-systemic vascular diseases ePAG

Luisa Maria Botella, Asociacion HTT Espana	**Caroline Van den Bosch**, HEVAS	**Paolo Federici**, Associazione Fondazione Italiana HHT 'Onilde Carini'	**Rafaella Restaino**, Fondazione Alessandra Bisceglia W ALE Onlus	**Juergen Grunert**, Ehlers-Danlos Initiative Deutschland e.V.	**Patrice Touboulie**, MARFANS	**Christina Grabowski,** Morbus Osler Selbsthilfe e.V.

Natascha Assies, NLNet	**Claudia Crocione**, Associazione Italiana Teleangectasia Emorragica	**Ange Van Der Velden,** LGD Alliance Europe	**Romain Alderweireldt,** ASBM Association Belge du Syndrome de Maran	**Valentina Favalli**, Magica Onlus	**Nele VERHAEGEN**, BeLymph

15 Rare neurological diseases ePAG

John Richard McFarlane, European Polio Union	**Isabella Brambilla**, Dravet Italia Onlus	**Tsvetana Schyns-Liharska**, European Network for Research on Alternating Hemiplegia	**Cathalijne Van Doorne**, euro-Ataxia and European Federation of Neurological Associations	**Piero Santantonio**, Mitocon Onlus	**Mary Kearney**, Friedreich's Ataxia Research Alliance Ireland

16 Rare neuromuscular diseases ePAG

François Lamy, AFM Téléthon	**Jean-Philipe Plançon**, French Association against Peripheral Neuropathies	**Massimo Marra**, CIDP Italia ONLUS	**Hannah Chalmers**, Muscular Dystrophy UK	**Evy Reviers**, ALS Liga Belgium	**Judit Varadine Csapo**, Angyalszarnyak Hungarian Muscle Dystrophy Association	**Marisol Montolio**, Duchenne Parent Project Spain

17 Rare renal diseases ePAG

Etienne Gosyns, Bruno Woitrin, Barrter and Gitelman (TBC)	**Marjolein Bos,** VKS-Cystinose Groep (TBC)	**Daniel Renault**, FEDERG	**Francisco Montfort/ Nacho Nunez,** aHUS (TBC)	**Claudia Sproedt**, Cystinose-Selbsthilfe e.V.	**Marjolein Storm,** Nierpatiënten Vereniging Nederland	**Marieke Vanmeel,** NephcEurope (TBC)	**Michel Schenkel, *ADPKD***

18 Rare skin disorders ePAG

Avril Kennan, DEBRA International	**Evanina Morcillo Makow,** DEBRA España	**Flavio Minelli**, Unione Italiana Ittiosi	**Ivonne Ronchetti**, PXE-Italy Onlus	**Geske Wehr,** Selbsthilfe Ichthyose e.V.	**Jose Manuel Montoya Gutierrez**, Asociacion de Afectados por Displasia Ectodermica

19 Rare urogenital diseases

Rita Serena Bartezzati, AICI Associazione Italiana Cistite Interstiziale	**Dalia Aminoff**, AIMAR	**Nicole Schwarzer**, SoMA e.V.	**Massimo Di Grazia**, Associazione Italiana Estrofia
Albert Otto Brinkmann, DSD Nederland			

20 Rare Pulmonary ERN

Fillipo Martone, Amici Contro la Sarcoidosi Italia Onlus	**Bernd Quadder,** Deutsche Sarkoidose-Vereinigung e.V. (DSV)	**Hilde De Keyser,** Cystic Fibrosis	**Luc Matthysen,** PHA Europe	**Pippa Powell** & **Sara Mansfield**, European Lung Foundation	**Gergely Meszaros,** PHA Europe **Marta Almagro,** ELF, Bronchiectasis Patient Advisory Group	**Kate Hill,** June Hancock Mesothelioma Research Fund
Bernd Stachetzki, Sarkoidose Netzwerk	**Dagmar Kauschka,** Lungfibrose e.V.	**Alessandro Carcano**, A.I.S.I.C.C.	**Carlee Gilbert**, ChILD EU	**Patrick Vandorpe**, HALO		**Pisana Ferrari**, PHA Europe
Liam Galvin, EU-IPFF	**Stefano Guerini**, Alfa1-AT Italia	**Edwin J. Brekelmans**, Alpha 1 Global	**Frank Willersinn,** Alpha 1 Global			

21 Rare Genetic Tumour Risk Syndromes ERN

Claas Röhl, NF Kinder – Verein zur Förderung der Neurofibromatoseforschung Österreich	**Anne Micallef,** Europa Donna	**Claudio Ales**, Associazione Italiana per la lotta alle PHTS	**Juergen Seppen,** Lynch-Polyposis

22 Rare Epilepsies

Isabella Brambilla, Dravet Italia Onlus	**Emma Williams,** Matthew's Friends	**Ashley Winslow/Carol Anne**, CDKL5	**Emma Nott/ Carrie Fulcher**, Hope for Hypothalamic Hamartoma

23 TRANSCHILD

Juan Fuertes, PHA Europe	**Pisana Ferrari**, PHA Europe	**Daniela Paulo,** Portuguese Children With Liver Disease (HEPATIX)	**Conchita Velázquez-Gaztelu**, NUPA	**Evy van Kempen,** Beleidsmedewerker Eigen Regie & Ervaringskennis delen

24 GUARD HEART

Edward Callus, European Congenital Heart Disease Organisation