

### 1. Rare Bone ePAG

<b>Inês Alves</b> , Fundación ALPE Acondroplasia	<b>Liesbeth Siderius</b> , Dutch Shwachman Diamond Patient Org	<b>Jean Moitry</b> , Association de L'Osteogenese Imparfaite	<b>Rebecca Tvedt Skarberg</b> , Osteogenesis Imperfecta Federation Europe
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### 2. Rare Cancer ePAG

<b>Kathy Oliver</b> , International Brain Tumour Alliance	<b>Isabelle Manneh-Vangramberen</b> , European Cancer Patient Coalition (ECPC)	<b>Estelle Lecointe-Artzner</b> , Sarcoma Patients EuroNet (SPAEN)	<b>Markus Wartenberg</b> , Sarcoma Patients EuroNet (SPAEN)	<b>Teodora Kolarova</b> , International Neuroendocrine Cancer Alliance (INCA)	<b>Catherine Bouvier</b> , International Neuroendocrine Cancer Alliance (INCA) & NET Patient Foundation UK	<b>Jo Grey</b> , AME ND UK	<b>Iain Galloway</b> , MPNE Ocular/ Rare
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### 3. Rare connective tissue and musculoskeletal diseases ePAG

<b>Charissa Frank</b> , Bindweefsel.be (Vlaamse Vereniging voor Erfelijke Bindweefselandoeningen vzw)	<b>Jürgen Grunert</b> , Deutsche Ehlers-Danlos-Initiative e.V.	<b>Marianne Riviere</b> , Association Française du Lupus et autres Maladies Auto-Immunes (AFL+)	<b>Ilaria Galetti</b> , SOSTIENI LA RICERCA PER LA SCLEROSI SISTEMICA - SCLERODERMIA
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### 4. Rare craniofacial anomalies and ENT (ear, nose and throat) disorders ePAG

<b>Sara Perez</b> , Asociación Nacional Síndrome de Joubert	<b>Gareth Davies</b> , European Cleft Organisation
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### 5. Rare endocrine diseases ePAG

<b>Johan de Graaf</b> , Nederlandse Hypofyse Stichting	<b>Jette Kristens</b>	<b>Johan Beun</b> , Bijniervereniging NVACP	<b>Petra Bruegmann</b>	<b>Diana Vitali</b> , Associazione Italiana
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		<b>en,</b> Addison Forening en i Danmark		Netzwerks Hypophysen- und Nebennieren erkrankunge n e. V.	Displasia Setto Ottica e Ipoplasiya del Nervo Ottico
<b>6. Rare eye diseases</b>					
<b>Christina Fasser &amp; Avril Daly,</b> Retina International	<b>Michael Längsfeld,</b> PRO RETINA Deutschland	<b>Paula Morandi,</b> MITOCON ONLUS	<b>Gaëlle Jouanjan,</b> FRANCE & ANIRIDIA EUROPE	<b>Daniela Brohlburg,</b> PRO RETINA Deutschland	<b>Russel Wheeler,</b> Leber's Hereditary Optic Neuropathy Society
<b>7. Rare gastrointestinal diseases</b>					
<b>Anke Widenmann-Grolig,</b> EAT The federation of Esophageal Atresia and Tracheo-esophageal fistula support groups e.V.		<b>Nicole Schwarzer,</b> SoMA for Hirschsprung Disease and Anorectal Malformation	<b>Bailly Vilette,</b> LEONORE	<b>Graham Slater, JoAnne Fruithof Frederic Armandm,</b> The Federation of Esophageal Atresia and Tracheo-Esophageal Fistula	
<b>Fanny Cauvet,</b> Association APEHDia	<b>Mrs. Antje Feldtmann-Korn,</b> KISE	<b>Benoit Decavele,</b> La Vie par un Fil			<b>Beverley Power,</b> CDH UK
<b>8. Rare Paediatric Cancer ePAG</b>					
<b>Anita Kienesberger, Stephanie Shremmer</b> Austrian Childhood Cancer Organization		<b>Luisa Basset,</b> Federación Española de Padres de Niños con Cáncer		<b>Lejla Kamerić,</b> Heart for kids with cancer in FBiH (Srce za djecu koja boluju od raka u FBiH)	
<b>9. Rare haematological diseases ePAG</b>					
<b>Amanda Bok,</b> European Haemophilia Consortium	<b>Jan Geissler,</b> Leukemia Patient Advocates Foundation	<b>Sophie Wintrich,</b> MDS UK Patient Support Group	<b>Angelo Loris Brunetta,</b> Associazione Ligure Thalassemicci Onlus	<b>Ananda Plate,</b> Myeloma Patients Europe	<b>Pierre Aumont,</b> Association de Soutien et d'Information à la Leucémie Lymphoïde

Chronique et la maladie de Waldenström

### 10 Rare hepatic diseases ePAG

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

<b>Renza Barbon Galluppi</b> , Associazione Italiana Sostegno Malattie Metaboliche Ereditarie Onlus	<b>Lut De Baere</b> , Belgische Organisatie voor Kinderen en Volwassenen met een Stofwisselingsziekte	<b>Vanessa Dos Reis Ferreira</b> , Portuguese Association for CDG	<b>Anne Hugon</b> , Association Francophone des Glycogenoses	<b>Anne-Sophie Lapointe</b> , Vaincre les Maladies Lysosomales	<b>Cinzia Arbellino</b> , MITOCON ONLUS	<b>Claudia Sproedt</b> , Cystinose-Selbsthilfe e.V.
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### 12 Rare immunological & auto inflammatory diseases ePAG

<b>Diana Marinello, Associazione Italiana Sindrome e Malattia di Behcet</b>	<b>John Mills, Vasculitis UK</b>	<b>Peter Verhoeven, Vasculitis Stichting</b>	<b>Richard West, Behcets International</b>	<b>Malena Vetterli, FMF &amp; AID</b>
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### 13 Rare malformations / developmental anomalies/and rare intellectual disabilities ePAG

<b>Tobias Arndt, European Dysmelia Reference Information Centre</b>	<b>Dorica Dan, Romanian Prader Willi Association</b>	<b>Gabor Pogany, Hungarian Williams Syndrome Association</b>	<b>Yvonne Milne, Rett Syndrome Europe</b>	<b>Ammi Andersson, International Federation Spina Bifida &amp; Hydrocephalus</b>	<b>Sue Routledge, Pitt Hopkins UK</b>	<b>Luis Quaresma, Portuguese Spina Bifida &amp; Hydrocephalus Association</b>
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### 14 Rare multi-systemic vascular diseases ePAG

<b>Luisa Maria Botella, Asociacion HTT Espana</b>	<b>Caroline Van den Bosch, HEVAS</b>	<b>Paolo Federici, Associazione Fondazione Italiana HHT 'Onilde Carini'</b>	<b>Rafaella Restaino, Fondazione Alessandra Bisceglia W ALE Onlus</b>	<b>Juergen Grunert, Ehlers-Danlos Initiative Deutschland e.V.</b>	<b>Patrice Touboulie, MARFANS</b>	<b>Christina Grabowski, Morbus Osler Selbsthilfe e.V.</b>
<b>Natascha Assies, NLNet</b>	<b>Claudia Crocione, Associazione Italiana Teleangectasi a Emorragica</b>	<b>Ange Van Der Velden, LGD Alliance Europe</b>	<b>Romain Alderweirdt, ASBM Association Belge du Syndrome de Maran</b>	<b>Valentina Favalli, Magica Onlus</b>		<b>Nele VERHAEGEN, BeLymph</b>

### 15 Rare neurological diseases ePAG

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

<b>François Lamy</b> , AFM Téléthon	<b>Jean-Philippe Plançon</b> , French Association against Peripheral Neuropathies	<b>Massimo Marra</b> , CIDP Italia ONLUS	<b>Hannah Chalmers</b> , Muscular Dystrophy UK	<b>Evy Reviers</b> , ALS Liga Belgiu m	<b>Judit Varadine Csapo</b> , Angyalszarnyak Hungarian Muscle Dystrophy Association	<b>Marisol Montolio</b> , Duchenne Parent Project Spain
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17 Rare renal diseases ePAG

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

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

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

## 20 Rare Pulmonary ERN

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

## 21 Rare Genetic Tumour Risk Syndromes ERN

<b>Claas Röhl</b> , NF Kinder – Verein zur Förderung der Neurofibromatoseforschung Österreich	<b>Anne Micallef</b> , Europa Donna	<b>Claudio Ales</b> , Associazione Italiana per la lotta alle PHTS	<b>Juergen Seppen</b> , Lynch- Polyposis
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## 22 Rare Epilepsies

<b>Isabella Brambilla</b> , Dravet Italia Onlus	<b>Emma Williams</b> , Matthew's Friends	<b>Ashley Winslow/Carol Anne</b> , CDKL5	<b>Emma Nott/ Carrie Fulcher</b> , Hope for Hypothalamic Hamartoma
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## 23 TRANSCHILD

<b>Juan Fuertes</b> , PHA Europe	<b>Pisana Ferrari</b> , PHA Europe	<b>Daniela Paulo</b> , Portuguese Children With Liver Disease (HEPATIX)	<b>Conchita Velázquez-Gaztelu</b> , NUPA	<b>Evy van Kempen</b> , Beleidsmedewerker Eigen Regie & Ervaringskennis delen
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24 GUARD HEART

**Edward Callus**, European Congenital Heart Disease Organisation