

1. Rare Bone ePAG

Inês Alves , Fundación ALPE Acondroplasia	Jean Moitry , Association de L'Osteogenese Imparfaite	Rebecca Tvedt Skarberg , Osteogenesis Imperfecta Federation Europe
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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
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3. Rare connective tissue and musculoskeletal diseases ePAG

Charissa Frank , Bindweefsel.be (Vlaamse Vereniging voor Erfelijke Bindweefselandoeningen 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
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4. Rare craniofacial anomalies and ENT (ear, nose and throat) disorders ePAG

Sara Perez , Asociación Nacional Síndrome de Joubert	Gareth Davies , European Cleft Organisation
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5. Rare endocrine diseases ePAG

Johan de Graaf , Nederlandse Hypofyse Stichting	Jette Kristensen , Addison Forening en i Danmark	Johan Beun , Bijniervereniging NVACP		Petra Bruegmann , Netzwerks Hypophysen- und Nebennierenerkrankungen e. V.	Diana Vitali , Associazione Italiana Displasia Setto Ottica e Ipoplasi del Nervo Ottico
6. Rare eye diseases					
Christina Fasser & Avril Daly , Retina International	Michael Längsfeld , PRO RETINA Deutschland	Paula Morandi , MITOCON ONLUS	Gaëlle 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		Graham Slater , The Federation of Esophageal Atresia and Tracheo-Esophageal Fistula	
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 Talassemici 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 Mishkovicj , NGO SLAP Save Liver Association Patients, Pr	Frank Willersinn , Alpha-1 Plus Belgium & Sandrine Lefrancois , Alpha 1 France
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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.
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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
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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	Yvonne Milne , Rett Syndrome Europe	Ammi Andersson , International Federation Spina	Sue Routledge , Pitt Hopkins UK	Luis Quaresma , Portuguese Spina Bifida &
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			Syndrome Association		Bifida & Hydrocephalus		Hydrocephalus Association
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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 Teleangectasi a 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
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16 Rare neuromuscular diseases ePAG

François Lamy , AFM Téléthon	Jean-Philippe Plançon , French Association against Peripheral Neuropathies	Massimo Marra , CIDP Italia ONLUS	Hannah Chalmers , Muscular Dystrophy UK	Evy Reviere , ALS Liga Belgium	Judit Varadine Csapo , Angyalszarn yak 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.				
20 Rare Pulmonary ERN							
		Hilde De Keyser , Cystic Fibrosis	Luc Matthysen , PHA Europe	Pippa Powell & Sara Mansfield ,	Gergely Meszaros , PHA Europe	Kate Hill , June Hancock	



EURORDIS Rare Diseases Europe

Fillipo Martone , Amici Contro la Sarcoidosi Italia Onlus	Bernd Quadder , Deutsche Sarkoidose-Vereinigung e.V. (DSV)			European Lung Foundation		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	Marta Almagro , ELF, Bronchiectasis Patient Advisory Group	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
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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
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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
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24 GUARD HEART

Edward Callus, European Congenital Heart Disease Organisation