



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
- **Elisabeth Martin**, Association Ollier-Maffucci Europe
- **Rebecca Tvedt Skarberg**, Osteogenesis Imperfecta Federation Europe
- **Tenna Toft Olesen**, XLH Patientenforeningen

- **Rare Cancer ePAG**

- **Catherine Bouvier**, NET patient Foundation UK
- **James Caldwell**, Northern Ireland Rare Disease Partnership
- **Iain Galloway**, MPNE Ocular/Rare
- **Stefan Gijssels**, Digestive Cancers Europe
- **Jo Grey**, Association for Multiple Endocrine Neoplasia Disorders
- **Emma Kinloch**, Adenoid Cystic Carcinoma
- **Teodora Kolarova**, International Neuroendocrine Cancer Alliance (INCA)
- **Estelle Lecoite**, ASSOCIATION FRANÇAISE DES PATIENTS DU GIST - ENSEMBLE CONTRE LE GIST
- **Isabelle Manneh-Vangramberen**, European Cancer Patient Coalition

- **Kathy Oliver**, International Brain Tumour Alliance (IBTA)
- **Roberto Persio**, Associazione Italiana Laryngectomizzati (AILAR)
- **Umberto Tassini**, Associazione Italiana Laryngectomizzati (AILAR)
- **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**
- **Alain Cornet**, Lupus Europe
- **Charissa Frank**, Vlaamse Vereniging voor Erfelijke Bindweefselaandoeningen
- **Ilaria Galetti**, Gruppo Italiano per la Lotta alla Sclerodermia ONLUS
- **Juergen Grunert**, Deutsche Ehlers-Danlos Initiative e. V.
- **Sander Otter**, Nationale vereniging voor LUPUS
- **Ana Vieira**, Liga Portuguesa contra as Doenças Reumáticas

- **Rare craniofacial anomalies and ENT disorders ePAG**
- **Gareth Davies**, European Cleft Organisation
- **Barbara Lieuwen**, Voorzitter Laposa
- **Thomas Luck**, Netzrverk Goldenhar-Syndrom und Ohrmuscheldysplasie e.V.
- **Sandra Mösche**, Elterninitiative Apert-Syndrom und verwandte Fehlbildungen e. V.
- **Sara Perez**, Asociación Nacional Síndrome de Joubert

- **Rare endocrine diseases ePAG**

- **Johan Beun**, Bijniervereniging NVACP
- **Petra Bruegmann**, European MEN Alliance
- **Manuela Brösamle**, AGS- Eltern- und Patienteninitiative e.V.
- **Patricia Carl**, Bundesverband Kleinüschsige Menschen und ihre Familien e.V.
- **Johan de Graaf**, Nederlandse Hypofyse Stichting (Dutch Pituitary Foundation)
- **Carole Delorme**, Association surénale
- **Elisabetta Freo**, L'Associazione Famiglie di Soggetti con Deficit dell'Ormone della Crescita ed altre Patologie
- **Jo Grey**, Association for Multiple Endocrine Neoplasia Disorders
- **Jette Kristensen**, Addison Foreningen i Danmark
- **Marika Porrey**, Schilddklier Organisatie Nederlande
- **Arlene Smyth**, Turner Syndrome Support Society

- **Marina Valenti**, Italian Association for Alstrom Syndrome
- **Diana Vitali**, SOD Italia - Associazione Italiana Displasia Setto Ottica e Ipoplasia del Nervo Ottico

- **Rare eye diseases ePAG**
- **Christina Fasser**, Retina International
- **Gaëlle Jouanjan**, FRANCE & ANIRIDIA EUROPE
- **Michael Längsfeld**, PRO RETINA Deutschland
- **Paula Morandi**, MITOCON ONLUS
- **Petia Stratieva**, Retina International
- **Dominique Sturz**, Usher Deafblind Forum Austria
- **Russel Wheeler**, Leber's Hereditary Optic Neuropathy Society

• Rare gastrointestinal diseases ePAG

- **Frederic Armand**, ASSOCIATION FRANÇAISE DE L'ATRÉSIE DE L'ŒSOPHAGE
- **Fanny Cauvet**, European Society of Pediatric Gastroenterology Hepatology and Nutrition
- **Benoit Decavele**, La Vie par un Fil
- **Antje Feldtmann-Korn**, Kise e.V
- **Joanne Fruithof**, The Federation of Esophageal Atresia and Tracheo-Esophageal Fistula Support Groups e.V.
- **Ester Garne**, UNIVERSITY OF SOUTHERN DENMARK
- **Annette Lemli**, Selbsthilfeorganisation für Menschen mit Anorektalfehlbildungen
- **Beverley Power**, CDH UK
- **Graham Slater**, The Federation of Esophageal Atresia and Tracheo-Esophageal Fistula Support Groups e.V.
- **Nicole Schwarzer**, Selbsthilfeorganisation für Menschen mit Anorektalfehlbildungen
- **Bailly Vilette**, Leonore
- **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**

- **Pierre Aumont**, Association de Soutien et d'Information à la Leucémie Lymphoïde Chronique et la maladie de Waldenström
- **Amanda Bok**, European Haemophilia Consortium
- **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

- **Rare hepatic diseases ePAG**

- **Barbara Borik**, Deutsche Morbus Crohn / Colitis ulcerosa Vereinigung (DCCV) e.V.
- **Robert Dixon**, PBC Foundation
- **Sandrine Lefrancois**, Alpha 1 France
- **Lone McColaugh**, Leverforeningen
- **Robert Mitchell Thain**, PBC Foundation
- **Biljana Mirceska**, NGO SLAP - Save Liver Association of Patients
- **Milan Mishkovikj**, NGO SLAP - Save Liver Association of Patients
- **Alison Taylor**, Children's Liver Disease Foundation

- **Rare hereditary metabolic disorders ePAG***
- **Renza Barbon**, UNIAMO
- **Lut de Baere**, BOKS
- **Tanya Collin**, European Gaucher Alliance
- **Rita Francisco**, APCDG
- **Anne Grethe Lauridson**, European Gaucher Alliance
- **Anne Hugon**, Association Francophone des Glycogénoses

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

- **Rare immunological & auto inflammatory diseases ePAG**
- **Zoi Anastasia**, Vasculitis UK
- **Jose Drabwell**, IPOPI - International Patient Organization for Primary Immunodeficiencies
- **Andrea Gressani**, Associazione per le immunodeficienze primitive Onlus
- **Diana Marinello**, Associazione Italiana Sindrome e Malattia di Behcet
- **Paul Morgan**, FMF & AID
- **Martine Pergent**, IPOPI - International Patient Organization for Primary Immunodeficiencies
- **Julie Power**, Vasculitis Ireland
- **Johan Prévot**, IPOPI - International Patient Organization for Primary Immunodeficiencies
- **Rachel Rimmer**, RACC – UK

- **Leire Solis**, IPOPI - International Patient Organization for Primary Immunodeficiencies
- **Peter Verhoeven**, Vasculitis Stichting
- **Malena Vetterli**, FMF & AID
- **Carlota Villar**, Barcelona PID Foundation

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

- **Claudio Ales**, Associazione Italiana per la lotta alle PHTS
- **Tobias Arndt**, European Dysmelia Reference Information Centre
- **Andrea Baines**, Angelman Syndrome Support Education and Research Trust
- **Lieven Bauwens**, International Federation for Spina Bifida and Hydrocephalus
- **Lisa Court**, Angelman Syndrome Support Education and Research Trust
- **Katie Cunnea**, Angelman Syndrome Support Education and Research Trust
- **Dorica Dan**, Romanian National Alliance for Rare Diseases
- **Rebecca Jenner**, Rett UK
- **Renée Jopp**, International Federation for Spina Bifida and Hydrocephalus
- **Nick Meade**, Genetic Alliance UK

- **Rachel Martin**, Angelman Syndrome Support Education and Research Trust
- **Pietro Marinelli**, ASSOCIAZIONE SMITH-MAGENIS ASM17 ITALIA ONLUS
- **Yvonne Milne**, Rett Syndrome Europe
- **Tina Nesbitt**, SWAN UK
- **Gabor Pogany**, FEWS - Federation of European Williams Syndrome
- **Lauren Roberts**, Swan UK
- **Sue Routledge**, Pitt Hopkins UK
- **Annalisa Scopinaro**, APWItalia
- **Beverly Searle**, Unique - The Rare Chromosome Disorder Support Group
- **Ammi Sundqvist**, International Federation for Spina Bifida and Hydrocephalus

- **Rare multi-systemic vascular diseases ePAG**

- **Romain Alderweireldt**, Association Belge du Syndrome de Marfan ASBL
- **Natascha Assies**, Nederlands Netwerk voor Lymfoedeem en Lipoedeem
- **Petra Borgards & Elisabeth Huhn**, Federal Association of Congenital Vasuclar Malformations
- **Luisa Botella**, Asociación HHT España
- **Claudia Crocione**, Associazione Italiana Teleangectasia Emorragica Italiana - HHT ONLUS
- **Elena de Moya Rubio**, MARFAN HILFE DEUTSCHLAND E.V.
- **Didier Erasme**, AMRO France
- **Karen Druckman**, HTT Swiss
- **Valentina Favalli**, Magica ONLU
- **Paolo Federici**, Associazione Fondazione Italiana HHT "Onilde Carini"
- **Charissa Frank**, Vlaamse Vereniging voor Erfelijke Bindweefselaandoeningen
- **Christina Grabowski**, HTT Europe
- **Juergen Grunert**, Deutsche Ehlers-Danlos Initiative e. V

- **Lex van der Heijden**, Cutis Marmorata Telangiectatica Congenita and other Vascular Malformations
- **Lise Murphy**, Svenska Marfanföreningen
- **Rafaella Restaino**, FONDAZIONE ALESSANDRA BISCEGLIA W ALE Onlus
- **Françoise Steinbach**, association marfans
- **Caroline Van Den Bosch**, HEVAS
- **Ange Van Der Velden**, Lymphangiomatosis & Gorham Disease Alliance Europe

- **Rare neurological diseases ePAG**
- **Astri Arnesen**, European Huntington Association
- **Monika Benson**, Dystonia Europe
- **Mary Kearney**, Friedreich's Ataxia Research Alliance Ireland (FARA)
- **Lori Renna Linton**, Euro-HSP
- **Lubomir Mazouch**, Spolek pro Atypické Parkinsonské syndromy
- **Amanda Rose**, Rare Dementia Support UK
- **Robert Scholten Apeldoorn**, Dutch Dystonia Association
- **Tsveta Schyns-Liharska**, European Network for Research on Alternating Hemiplegia, ENRAH
- **Cathalijne van Doorne**, euro-Ataxia and European Federation of Neurological Associations

- **Rare neuromuscular diseases ePAG**
- **Bobby Ancil**, Muscular Dystrophy UK
- **Mencía de Lemus Belmonte**, Fundame Spain/SMA Europe
- **Emma Del Rey**, French Association for Mitochondrial Diseases
- **Dimitrios Athanasiou**, MDA Hellas/UPPMD
- **Marguerite Friconneau**, AFM-Téléthon
- **Joaquim Brites**, Associacao Portuguesa de Neuromusculares
- **Ria Broekgaarden**, Dutch Patient Society of Neuromuscular Diseases
- **Nic Bungay**, Muscular Dystrophy UK
- **Rosanna Fodera**, MITOCON ONLUS
- **Madelon Kroneman**, Spierziekten Nederland
- **François Lamy**, AFM-Téléthon
- **Massimo Marra**, CIDP Italia Onlus
- **Alexandre Mejat**, AFM-Téléthon
- **Marisol Montolio**, Duchenne Parent Project Spain

- **Françoise Pelcot**, French Association Against Amyloidosis
- **Alejandra Pereda**, Duchenne Parent Project Spain
- **Francisco Javier Pérez-Mínguez**, 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**

- **Marjolein Bos**, VKS-Cystinose Groep
- **Suzanna Carvajal Arjona**, Hipofam
- **Marie Jeanne Pierrat**, CAKUT
- **Michel Schenkel**, FEDERG - Federation of European associations of patients affected by renal diseases
- **Claudia Sproedt**, Cystinose Selbsthilfe e.V.
- **Harris Tess**, Ciliopathy Alliance
- **Evy van Kempen**, Nierpatiënten Vereniging Nederland (Dutch Kidney Patients Association)
- **Marieke van Meel**, NephcEurope

- **Rare Skin Disorders ePAG**
- **Mandy Aldwin**, European Network for Ichthyosis
- **Wafa Chaabi**, Enfants de la Lune Association pour le Xeroderma Pigmentosum
- **Marie-Claude Boiteux**, Cutis Laxa Internationale
- **Laurence Gallu**, Association Pemphigus – Pemphigoïdes France
- **Olivia Gross-Khalifa**, Association Française des Dysplasies Ectodermiques
- **Ulrike Holzer**, Selbsthilfegruppe Ektodermale Dysplasie e.V.
- **Ingrid Jageneau**, Debra Belgium vzw
- **Hans Jörg Kunte**, German Self Aid Group for Adamantiades-Behcet's Disease
- **Sophie Le Pallec**, ASSOCIATION ANALYSTE
- **Flavio Minelli**, Unione Italiana Ittiosi
- **Jacques Monnet**, Incontinentia Pigmenti France

- **Jose Manuel Montoya Gutierrez**, Asociación de Afectados por Displasia Ectodérmic
- **Evanina Morcillo Makow**
- **Christian Moser**, Freu(n)de Mondscheinkinder
- **Cinzia Pilo**, DEBRA Italia ONLUS – Associazione per la Ricerca sull’Epidermolisi Bollosa
- **Clare Robinson**, DEBRA UK
- **Ivonne Ronchetti**, PXE-Italy
- **Francesca Sofia**, DEBRA Italia ONLUS – Associazione per la Ricerca sull’Epidermolisi Bollosa
- **Bente Villumsen**, Hidrosadenitis-Denmark
- **Giulia Volpato**, p63 EEC Syndrome International network word communication
- **Jodi Whitehouse**, Caring Matters Now

- **Rare urogenital diseases ePAG**
 - **Dalia Aminoff**, AIMAR
 - **Serena Bartezzati**, AICI Associazione Italiana Cistite Interstiziale
 - **Jurgen Hensen**, ICA Deutschland
 - **Annette Lemli**, Selbsthilfeorganisation für Menschen mit Anorektalfehlbildungen

- **Rare Pulmonary ePAG**

- **Marta Almagro**, European Lung Foundation
- **Alessandro Carcano**, Associazione Italiana Per La Sindrome Da Ipoventilazione Centrale Congenita
- **Hilde de Keyser**, Association Muco Vereniging
- **Pisana Ferrari**, ASSOCIAZIONE IPERTENSIONE POLMONARE ITALIANA
- **Liam Galvin**, Irish Lung Fibrosis Association
- **Carlee Gilbert**, ChILD Lung Foundation
- **Kate Hill**, June Hancock Mesothelioma Research Fund
- **Dagmar Kauschka**, ERWACHSENEN-HISTIOZYTÖSE X E.V.
- **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

- **Cassidy Nicola**, Irish Lung Fibrosis Association
- **Marjo Poulissen**, Longfonds
- **Bernhard Rindlisbacher**, KARTAGENER SYNDROM & PRIMÄRE CILIÄRE DYSKINESIE(E.V.)
- **Bernd Stachetzki**, Sarkoidose Netzwerk
- **Guerini Stefano**, ASSOCIAZIONE NAZIONALE ALFA₁-AT
- **Patrick Vandorpe**, HALO

- **Rare Genetic Tumour Risk Syndromes ePAG**
- **Claudio Ales**, Associazione Italiana per la lotta alle PHTS
- **Tamara Hussong Milagre**, Evita (Portuguese Association of carriers of genetic mutations related to Hereditary Cancer)
- **Anne Micallef**, Europa Donna
- **Stefania Mostaccioli**, Lega per la Neurofibromatosi 2-OnlusItalian
- **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

- **Rare Epilepsies ePAG**

- **Isabella Brambilla**, Dravet Italia Onlus
- **Nathalie Coque**, Alliance Syndrome Dravet
- **Myra de Groot**, DSEF
- **Anne-Sophie Hallet**, Alliance Syndrome de Dravet
- **Judette Lancrenon**, The Paratonnerre Association for FIRES
- **Fabrizio Mistretta**, Insieme per la Ricerca PCDH19 Onlus
- **Barbara Nicol**, Purple Day Spain
- **Carol Anne Partridge**, CDKL5
- **Allison Watson**, Ring 20 UK
- **Emma Williams**, Matthew's Friends

- **Transplantation in Children ePAG***
- **Matilde Correia**, Associação Portuguesa de Insuficientes Renais
- **Pisana Ferrari**, PHA Europe
- **Juan Fuertes**, PHA Europe
- **Nana Gomex Mayoral**, HEPA
- **Sandrine Lefrancois** - Association ADAAT Alpha1-France
- **Daniela Paulo**, Portuguese Children With Liver Disease (HEPATIX)
- **Stefano Pavanello**, Unione Trapiantati Polmone di Padova
- **Alba Santos**, NUPA
- **Alison Taylor**, Children's Liver Disease Foundation Diverse Disease
- **Evy van Kempen**, Beleidsmedewerker Eigen Regie & Ervaringskennis delen
- **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
- **Max Groenhart**, Harteraad
- **Simone Louisse**, Stichting Hart4Onderzoek
- **Peter Nordqvist**, Swedish Heart Foundation
- **Sophie Pierre**, Association des Maladies héréditaires du Rythme Cardiaque
- **Marion Van Sintruije**, Harteraad
- **Patricia Vlasman**, Harteraad
- **Dayenne Zwaagman**, Stichting Hart4Onderzoek