



ePAGs

Grouped per country

Updated: 05/07/202

EURORDIS.ORG



Directory of ePAG [[European Patient Advocacy Groups](#)] representatives

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**.

Austria

Ulrike	Holzer	Selbsthilfegruppe Ektodermale Dysplasie e.V.
Anita	Kienesberger	Österreichische Kinder-Krebs-Hilfe
Ernst	Leitgeb	Svenska Ödemförbundet (Swedish Association of Chronic Oedema)
Lori	Renna Linton	European Federation for Hereditary Spastic Paraplegia
Claas	Röhl	NF Kinder – Verein zur Förderung der Neurofibromatoseforschung Österreich
Dominique	Sturz	Usher Deafblind Forum Austria

Belgium

Romain	Alderweireldt	Association Belge du Syndrome de Marfan Asbl
Maria	Barea	Vascular Anomaly Patient Association
Monika	Benson	Dystonia Europe
Alain	Cornet	Association Lupus Erythematosus
Lutgarde	De Baere	Belgische Organisatie Voor Kinderen En Volwassenen Met Een Stofwisselingsziekte
Hilde	De Keyser	Association Muco Vereniging
Charissa	Frank	Vlaamse Vereniging voor erfelijke Bindweefselaandoeningen
Stefan	Gijssels	Digestive Cancers Europe
Ingrid	Jageneau	Debra Belgium VZW
Renée	Jopp	International Federation For Spina Bifida And Hydrocephalus
Luc	Matthysen	Association De Patients Souffrant D'Hypertension Artérielle Pulmonaire En Belgique
Ananda	Plate	Myeloma Patients Europe
Evy	Reviere	ALS Liga België
Leire	Solis Garate	IPOPI
Patrick	Vandorpe	Halo vzw

Bosnia and Herzegovina

Lejla	Kameric	Srce Za Djecu Koja Boluju Od Raka U Fbih (Heart For Kids With Cancer In Fbih)
-------	---------	---

Bulgaria

Teodora	Kolarova	International Neuroendocrine Alliance
Petia	Stratieva	Retina International

Cyprus

Marios

Vakanas

Association of Patients & Friends of Imd "Aspida Zois"

Czechia

Lubomir	Mazouch	Rare Diseases Czech Republic (Ceska Asociace Pro Vzacna Onemocneni)
---------	---------	---

Denmark

Pernille	Henriksen	Dansk Lymfødem Forening
Jette	Kristensen	Asociación Española De Ayuda A Niños Con Enfermedades Hepáticas Y Trasplantados Hepáticos
Anne-Grethe	Lauridsen	Gaucher Foreningen I Danmark
Lone	Mccolaugh	Leverforeningen
Inge	Schalkers	Harteraad
Tenna	Toft Olesen	MPNE Ocular/Rare
Lisbeth	Vestergaard Andersen	June Hancock Mesothelioma Research Fund
Bente	Villumsen	HHT Denmark

Finland

Alva	Fontel	Epilepsialiitto - Finnish Epilepsy Association
Jaana	Grönholm	Cardiac Risk In The Young
		Asociación Galega de Linfedema, Lipedema, Insuficiencia Venosa Crónica y otras Patologías Vasculares Periféricas
Katja	Laine	
Anna	Meriluoto	Fabry International Network
Mailis	Sohonon	European Cleft Organisation
		European Network of Gynaecological Cancer Advocacy Groups
Eva-Maria	Strömsholm	

France (1)

Pierre	Aumont	Association de Soutien et d'Information a la Leucémie Lymphoïde Chronique
Beate	Bartés	Vivre sans Thyroïde
Marie-Claude	Boîteux	Cutis Laxa Internationale
Fanny	Cauvet	European Society Of Pediatric Gastroenterology Hepatology And Nutrition
Sandrine	Daugy	Génération 22
Myra	De Groot	Asociación Catalana De Enfermedades Neuromusculares
Emma	Del-Rey	National Association of Sufferers of Lymphatic Disorders
Marie	Devaux	Association Les Feux Follets
Luigi	Distefano	Association Française Niemann Pick
Nathalie	Ferard	Síndromes Arrítmicos Relacionados Con La Muerte Súbita
Michel	FRANCOIS	Association nationale pour la promotion et le developpement de la langue francaise parlee completee
Marguerite	Friconneau	Association Française contre les Myopathies - Téléthon
Laurence	Gallu	Association Pemphigus – Pemphigoïdes France
Jeremie	Gautreau	Association Française Contre Les Neuropathies Périphériques
Anne	Gregoriades	Vaincre Les Maladies Lysosomales
Carole	Herman	Alpha 1 Global

France (2)

Gaëlle	Jouanjan	Geniris
François	Lamy	Association Française contre les Myopathies - Téléthon
Estelle	Lecoïnte	Sarcoma Patients Euronet
Sandrine	Lefrançois	Alpha 1 France
Elisabeth	Martin	Association Ollier Maffucci Europe
Alexandre	Mejat	Association Française contre les Myopathies - Téléthon
Marie-Christine	Ouillade	Association Française contre les Myopathies - Téléthon
Françoise	Pelcot	Europa Donna Slovenia
Martine	Pergent	Asociación HHT España
Sophie	Pierre	Association Française des Maladies Héréditaires du Rythme Cardiaque
Jean-Philippe	Plançon	Association Française Contre Les Neuropathies Périphériques
Daniel	Renault	Association pour l'information et la recherche sur les Maladies Rénales Génétiques
Jacques	Salama	Association Française contre les Myopathies - Téléthon
Angélique	Sauvestre Varela	Debra France
Sandrine	Segovya-Kueny	Association Française contre les Myopathies - Téléthon
Françoise	Steinbach	Association Marfans
Daniel	Tanesse	Charcot-Marie-Tooth France
Camille	Therond-Charles	Association Maladies Foie Enfants

Germany (1)

Conny	Aust	Selbsthilfegruppe Blasenektrophie/ Epispadie e.V. International Patient Organization for Primary Immunodeficiencies
Ruth	Biller	
Alena	Blaß	Selbsthilfegruppe für komplementbedingte Erkrankungen e.V.
Petra	Borgards	Bundesverband für Angeborene Gefäßfehlbildungen e.V.
Edwin	Brekelmans	European Lung Foundation
Manuela	Broesamble	Ags-Eltern- Und Patienteninitiative E.V.
Petra	Bruegmann	Netzwerk Hypophysen- und Nebennierenerkrankungen e. V.
Patricia	Carl	BKMF e.V
Elena	De Moya Rubio	Marfan Hilfe Deutschland e.V.
Jan	Geissler	Leukämie-Online E.V
Christina	Grabowski	HHT Europe
Jüergen	Grunert	Deutsche Ehlers-Danlos Initiative e.V.
Marija	Joldić	MPS Europe
Anne	Kalweit	Pnh Support
Dagmar	Kauschka	Erwachsenen-Histiozytose X E.V.
Martha	Kirchhoff	Phosphatdiabetes E.V.
Michael	Längsfeld	Pro Retina Deutschland e.V.
Thomas	Luck	Netzwerk Goldenhar-Syndrom Undohrmuscheldysplasie E.V.
Rita	Magenheim	German Li Fraumeni Association

Germany (2)

Carina	Mainka	KIF11 Kids e.V.
Elena	Matta	Lymphido
Christiane	Mockenhaupt	Selbsthilfegruppe für komplementbedingte Erkrankungen e.V.
Sandra	Mösche	Retina International
Wiebke	Papenthin	Asociación por la vida con GLUT-1 "AGLUTINATE"
Marek	Parowicz	Polskie Stowarzyszenie Na Rzecz Osób Z AHC
Bernd	Quadder	Deutsche Sarkoidose Vereinigung e.V.
Nicola	Reents	Familienhilfe Darmkrebs E.V. / Semi-Colon
Bernhard	Rindlisbacher	Kartagener Syndrom & Primäre Ciliäre Dyskinesie(E.V.)
Johanna	Rohlfing	Federación Española de Enfermedades Neuromusculares
Thomas	Schaller	Pompe Deutschland E.V.
Nicole	Schwarzer	Selbsthilfeorganisation für Menschen mit Anorektalfehlbildungen
Inge	Schwersenz	Initiative 'Forschung Und Therapie Für SMA'
Claudia	Sproedt	Cystinose Selbsthilfe e.V.
Bernd	Stachetzki	Sarkoidose Netzwerk
Leona	Wagner	Asociacion Española De Ayuda A Niños Con Trasplante Multivisceral Y Afectados De Fallo Intestinal Y Alimentación Parenteral
Markus	Wartenberg	Sarcoma Patients Euronet
Anke	Widenmann-Grolig	The Federation of Esophageal Atresia and Tracheo-Esophageal Fistula Support Groups e.V.
Anna	Wiegandt	Selbsthilfe Ichthyose e.V.
Petya	Zyumbileva	Melanom Info Deutschland

Greece

Dimitrios Athanasiou

World Duchenne Organization

Hungary

Gergely	Meszaros	PHA Europe
Gabor	Pogany	Hungarian Williams Syndrome Association
Judit	Varadine Csapo	Angyalszarnyak Hungarian Muscle Dystrophy Association

Ireland

Nicola	Cassidy	Irish Lung Fibrosis Association
Alan	Finglas	International Brain Tumour Alliance
Liam	Galvin	European Idiopathic Pulmonary Fibrosis & Related Disorders Federation
Mary	Kearney	Friedreich'S Ataxia Research Alliance
Julie	Power	Vasculitis Ireland Awareness

Italy (1)

Claudio	Ales	Associazione Italiana per la lotta alle PHTS
Dalia-Aimar	Aminoff	Associazione Italiana per le Malformazioni Anorettali
Rita Serena	Bartezzati	Associazione Italiana Cistite Interstiziale
Isabella	Brambilla	Dravet Italia Onlus
Loris Angelo	Brunetta	Associazione Ligure Talassemici Onlus
Edward	Callus	European Congenital Heart Disease Organisation
Alessandro	Carcano	Verein Lichen Sclerosus
Duccio	Cavalieri	Associazione Italiana Morbo di Hirschsprung
Valeria	Corradin	Associazione Italiana Lipodistrofie
Claudia	Crocione	HHT Europe
Fernanda	de Angelis	Parent Project Onlus
Simone	de Vergori	Associazione Cardiomiopatie E Malattie Rare Connesse
Paolo	Federici	Associazione Fondazione Italiana HHT "Onilde Carini"
Pisana	Ferrari	PHA Europe
Rosanna	Foderà	Mitocon- Insieme per lo Studio e la Cura delle Malattie Mitocondriali - Onlus
Elisabetta	Freo	Muscular Dystrophy Uk
Ilaria	Galetti	Gruppo Italiano per la lotta alla Sclerodermia Onlus
Flavia	Galletti	Associazione Italiana Rene Policistico Onlus
Andrea	Gressani	Associazione per le Immunodeficienze Primitive Onlus
Stefano	Guerini	Associazione Nazionale Alfa1-At

Italy (2)

Monica		
Christine	Lucente	Associazione Italiana Glut1
Pietro	Marinelli	Associazione Smith-Magenis Asm17 Italia Onlus
Diana	Marinello	Behcets International
Massimo	Marra	CIDP Italia Onlus
Filippo	Martone	Amici Contro La Sarcoidosi Italia Onlus
Stefania	Mostaccioli	Lega Per La Neurofibromatosi 2-Onlus
Michela	Onali	Gli Equilibristi HIBM
Stefano	Pavanello	Unione Trapiantati Polmone Di Padova
Roberto	Persio	Associazione Italiana Laryngectomizzati
Laura	Rossi Brunori	Associazione Italiana Gaucher Onlus
Annalisa	Scopinaro	Associazione Persone Williams Italia Onlus
Silvia	Sestini	Associazione Italiana Malati di Alcaptonuria
Stefania	Tobaldini	Associazione Italiana Anderon-Fabry
Francesca		
Romana	Torracca	Associazione Pazienti della Sindrome di Churg Strauss
Manuela	Vaccarotto	Associazione Italiana Sostegno Malattie Metaboliche Ereditarie Onlus
Marina	Valenti	Italian Association For Alstrom Syndrome
GIULIANA	VALERIO	Associazione Italiana Sostegno Malattie Metaboliche Ereditarie Onlus
Rosaria	Vavassori	IAHCRC CONSORTIUM
Diana	Vitali	SOD Italia - Associazione Italiana Displasia Setto Ottica e Ipoplasi del Nervo Ottico
Giulia	Volpato	P63 EEC Syndrome International Net Work Word Communication - Malattie Rare Onlus

Latvia

Baiba

Ziemele

Latvia Hemophilia Society

Lithuania

Davidonis	Martynas	Fabry International Network
Kristina	Zaveckiene	Lithuanian Children's Cancer Association

Luxembourg

Anne

Goeres

Fondatioun Kriibskrank Kanner

Malta

Anne	Micallef	Europa Donna - The European Breast Cancer Coalition
------	----------	---

Netherlands (1)

Johan	Beun	Associação Portuguesa De Insuficientes Renais
Patricia	Blomkwist-Markens	Gbs/Cidp Support Group Uk
Marjolein	Bos	Vks-Cystinose Groep
Johan	De Graaf	Asociacion Española De Ayuda A Niños Con Trasplante Multivisceral Y Afectados De Fallo Intestinal Y Alimentación Parenteral
Ingrid	de Groot	Vereniging Spierziekten Nederland - Dutch Association for Neuromuscular Disease
Hanka	Dekker	Volwassenen, Kinderen En Stofwisselingsziekten
Dirk-Jan	Gloudemans	Vereniging Ziekte Van Hirschsprung
Christiaan	Groen	Salivary Gland Cancer UK
Eline	Hoogstra	Nederlands Netwerk Voor Lymfoedeem En Lipoedeem
Saara	Kiema	IPOPI
Diana	Kim	Asociación por la vida con GLUT-1 "AGLUTINATE"
Gerritjan	Koekkoek	Net Patient Foundation Uk
Madelon	Kroneman	Vereniging Spierziekten Nederland - Dutch Association for Neuromuscular Disease
Merinke	Kuiper-Lenters	Asociación Española De Enfermos De Glucogenosis
Barbara	Lieuwen	Landelijke Patiënten- En Oudervereniging Voor Schedel- En/ Of Aangezichtsafwijkingen.

Netherlands (2)

Simone	Louisse	Stichting Hart4Onderzoek / Heart4Research
Diana	Maas	Contactgroep Marfan Nederland
Anita	Noordhoff	Epilepsiefonds
Marjo	Poulissen	Longfonds
Judith	Taylor	Thyroid Cancer Alliance
Erica	Van De Mheen	Duchenne Parent Project España
Caroline	Van Den Bosch	Hevas
Lex	Van Der Heijden	CMTC-OVM
		Nierpatiënten Vereniging Nederland (Dutch Kidney Patients Association)
Evy	Van Kempen	
Marjolein	Van Kessel	Naevus Global
Marieke	Van Meel	Nephceurope
Karin	Veldman	Vereniging voor Ichthyosis Netwerken
Gerard	Wellenberg	Myotonic Dystrophy Support Group
Jose	Willemse	Nederlandse Leverpatienten Vereniging
Dayenne	Zwaagman	Stichting Hart4Onderzoek / Heart4Research

North Macedonia

Biljana Mirceska

Save Liver Association Of Patients
With Liver Diseases

Norway

Astri	Arnesen	<u>European Huntington Association</u>
Rebecca		
Tvedt	Skarberg	OIFE - Osteogenesis Imperfecta Federation Europe
Dag		European Federation of Associations of Patients with
Erling	Stakvik	Haemochromatosis

Portugal

Ines	Alves	Associação Nacional De Displasias Ósseas
Joaquim	Brites	Associação Portuguesa De Doentes Neuromusculares
		Associação Portuguesa CDG e Outras Doenças Metabólicas
Dorinda	Dams Silva	
João	de Sousa e Silva	Associação Portuguesa De Neurofibromatose
		Associação Portuguesa CDG e Outras Doenças Metabólicas
Rita	Francisco	
Vera	Guimaraes	Liga Portuguesa contra as Doenças Reumáticas
Tamara	Hussong Milagre	EVITA
Manuela	Lourenço Marques	National Association of Sufferers of Lymphatic Disorders
		Rarissimas - Associação Nacional De Deficiências Mentais E Raras
Nuno	Marques	
Matilde	Marques Correia	Associação Portuguesa De Insuficientes Renais
Johan	Prévot	IPOPI
Ana	Vieira	Liga Portuguesa contra as Doenças Reumáticas

Romania

Dorica	Dan	Romanian Prader Willi Association
Isabela	Tudorache	Parent Project Romania - Association For Research And Support In Muscular Dystrophy

Slovenia

Tanja

Spanic

Europa Donna Slovenia

Spain (1)

Silvia	Aguilera	Asociación Española Del Síndrome De Rett
Luisa	Basset Salom	Federacion Espanola De Padres Con Ninos Con Cancer
Luisa- Maria	Botella	Asociación HHT España
Sandra	Brasil	FMF & AID Global Association
Suzanna	Carvajal Arjona	Hipofam
Beatruice	Casado Verrrier	Familias GA
Ester	Costafreda	Síndromes Arrítmicos Relacionados Con La Muerte Súbita
Mencía	de Lemus Belmonte	Fundación Atrofia Muscular Espinal
Covadonge	Diaz Martinez	Asociación por la vida con GLUT-1 "AGLUTINATE"
Juan	Fuertes	PHA Europe
Araceli (Nana)	Gomez Mayoral	Asociación Española De Ayuda A Niños Con Enfermedades Hepáticas Y Trasplantados Hepáticos
Juan M.	Lameiro Barreiro	Asociación Galega de Linfedema, Lipedema, Insuficiencia Venosa Crónica y otras Patologías Vasculares Periféricas

Spain (2)

Enrique	Landilo Contreras Pulido	Asociación Española De Enfermos De Glucogenosis
Marisol	Montolio	Duchenne Parent Project España
Jose Manuel	Montoya Gutierrez	Asociación de Afectados por Displasia Ectodérmica
Barbara	Nicol	Purple Day Spain
Alexander	Niehaus	Asociación por la vida con GLUT-1 "AGLUTINATE"
Alejandra	Pereda	Duchenne Parent Project España
Sara	Perez Martinez	Asociación Nacional Síndrome de Apert
Francisco		Parent Project Romania - Association For Research And Support
Javier	Pérez-Mínguez	In Muscular Dystrophy
Leticia	San Jose	ASEM Cataluña
Alba R	Santos	Asociacion Española De Ayuda A Niños Con Trasplante Multivisceral Y Afectados De Fallo Intestinal Y Alimentación Parenteral
Sandra	Beltran	Asociacion Española De Ayuda A Niños Con Trasplante Multivisceral Y Afectados De Fallo Intestinal Y Alimentación Parenteral
Núria	Tarrats	DEBRA Spain
Carlota	Villar	Barcelona Pid Foundation

Sweden

Ammi	Andersson-Sundqvist	International Federation For Spina Bifida And Hydrocephalus
Peter	Hall	Svenska Ödemförbundet (Swedish Association of Chronic Oedema)
Peter	Nordqvist	The Swedish Heart-Children's Association

Switzerland

Christina	Fasser	Retina International
Michael	Männer	Verein Lichen Sclerosus
Karen	Topaz Druckman	HHT-Swiss
Malena	Vetterli	FMF & AID Global Association

UK (1)

Marta	Almagro	European Lung Foundation
Bobby	Ancil	Muscular Dystrophy Uk
Julia	Boonnak	Cdg Uk
Catherine	Bouvier	Net Patient Foundation Uk
Nic	Bungay	Muscular Dystrophy Uk
James	Caldwell	Northern Ireland Rare Disease Partnership
Tanya	Collin-Histed	International Gaucher Alliance
Steven	Cox	Cardiac Risk In The Young
Gareth	Davies	European Cleft Organisation
Jose	Drabwell-Wuite	Asociación Española Del Síndrome De Rett
		Associazione Pazienti della Sindrome di Churg
Eugenia	Durante	Strauss
Iain	Galloway	MPNE Ocular/Rare
Carlee	Gilbert	Asociación de Afectados por Displasia Ectodérmica
		Association for Multiple Endocrine Neoplasia
Jo	Grey	Disorders
Tess	Harris	Ciliopathy Alliance

UK (2)

Kate	Hill	June Hancock Mesothelioma Research Fund
Emma	Kinloch	Salivary Gland Cancer UK
Daniel	Lewi	The Cure & Action For Tay-Sachs (Cats) Foundation
Toni	Mathieson	Liga Portuguesa contra as Doenças Reumáticas
Lisa	Matthew	no patient organisation
Yvonne	Milne	Rett Syndrome Europe
Paul	Morgan	FMF & AID Global Association
Emma	Nott	Hope for Hypothalamic Hamartomas UK
Karen	O'Hara	Muscular Dystrophy Uk
Kathy	Oliver	International Brain Tumour Alliance
Carol-Anne		
Anne	Partridge	Cdkl5 Uk
Diana	Perry	Ectodermal Dysplasia Society
Maria	Piggin	PNH Support
Pippa	Powell	European Lung Foundation
Beverley	Power	CDH Uk

UK (3)

Rachel	Rimmer	Cdg Uk
Torie	Robinson	Epilepsy Sparks
June	Rogers	The Cure & Action For Tay-Sachs (Cats) Foundation
Sue	Routledge	Pitt Hopkins UK
Graham	Slater	The Federation of Esophageal Atresia and Tracheo-Esophageal Fistula Support Groups e.V.
Arlene	Smyth	Turner Syndrome Support Society
Richard	Stamp	Niemann-Pick Disease Group UK
Alison	Taylor	Children's Liver Disease Foundation
Martine	Walmsley	PSC Support
Allison	Watson	Ring 20 Research and Support UK CIO
Dominic	Wells	Muscular Dystrophy Uk
Russell	Wheeler	Leber's Hereditary Optic Neuropathy Society
Jodi	Whitehouse	Caring Matters Now
Emma	Williams	Matthew'S Friends For Ketogenic Dietary Therapies
Sophie	Wintrich	MDS Alliance
Anastasia	Zografia	The Swedish Heart-Children's Association - Hjärtebarnsföreningen