

EURORDIS Open Letter signatures

List of organisations represented by the signatories of the Open Letter:

A.C.A.R. Onlus	Altro
Association Luxembourgeoise d'aide aux Enfants Cardiaques	Association aidante les familles et personnes concernées
Aismo	Associazione
Thélema - Psicoterapia e Riabilitazione	Centro di cura e di ricerca
Charitable Foundation Orphanni Synytsi	Charitable foundation
Association luxembourgeoise du Syndrome de Rett	Charity body
Lgmd CAB	Community advisory Board
Equipe Relais Handicaps Rares	coordination of way for people with disabilities
A.C.A.R.	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Acar Aps	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
All Ireland Rare Diseases Interdisciplinary Research Network	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Alliance of Rare Liver Diseases from Moldova	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Anticancer Fund	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Antwerp University Hospital	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
asociacion de enfermos de wilson	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Asociația PENTRU MATEI	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student

Associação EVITA - Cancro Hereditário	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Belgian Heart Ligue & Hôpital universitaire de Bruxelles, Université libre de Bruxelles	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
BNDMR	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
centre for developmental disabilities - University Hospitals Leuven	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
CHU Brugmann	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
CHU Brugmann/ CHU StPierre Bruxelles	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Cystic Fibrosis Armenian center	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Department of Respiratory Medicine, Ghent Univeristy Hospital	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Department of Respiratory Medicine, University hospital Leuven	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Dept Rheumatology, Universitatea de Medicina si Farmaciu Iuliu Hatieganu, Cluj, ERN REConnet centre	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ENDO ERN	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Endo-ERN	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ERKNET	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ERN BOND	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ERN CRANIO	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ERN EpiCARE	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student

ERN EURO-NMD	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ERN EuroBloodNET	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ERN eUROGEN	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ERN GENTURIS	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ERN GUARD Heart	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ERN ITHACA	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ERN-EuroBloodNet	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ERN-RITA	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ERN-Skin	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Ernithaca	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
eUROGEN	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
FH TURKEY	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
FMF & AID Global Association	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Forum Seltene Krankheiten - www.forum-sk.at	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Foundation 29	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Foundation for Biomedical Research and Innovation at Kobe	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student

Frambu competence centre for rare diagnosis	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Friedreich's Ataxia Research Alliance Ireland	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
FUNDACION ECO	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Hospital Universitari de Bellvitge	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Hospital Universitario de Bellvitge	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Institut des Maladies rares	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Instytut Gruźlicy i Chorób Płuc , Warsaw, Poland	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
ITHACA Romania	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
John Walton Muscular Dystrophy Research Centre	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
June Hancock Mesothelioma Research Fund	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Khmelnysky rare diseases center	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Khmelnyskyi City Children's Hospital	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Koc university	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Life and Health Sciences Research Institute, University of Minho	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Lithuanian Ophthalmological Society	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Lithuanian Society of Pulmonology and Allergy	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student

Lithuanian Society of Rare Respiratory Diseases	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Medical university - Sofia	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
MetabERN	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Mexican Association of Human Genetics	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Mijnlever vzw	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
National Institute of Children's Diseases, Pediatric Ophthalmology Department	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Nephie e.V. - Selbsthilfe nephrotisches Syndrom	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Neuromuscular Center and ERN EURO-NMD Strasbourg, France	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Norwegian National Advisory unit on Rare Disorders	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
NPO for promotion of health and cure of OPMD	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Pediatric Cardiac Center, National Institute of Cardiovascular Diseases	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
PKS	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Romanian Gaucher Association (Asociatia Gaucher Romania)	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Sciensano, Orphanet Belgium	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Siena Referral centre Rare Lung diseases	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
European Society for Paediatric Oncology (SIOPE)	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student

Stichting HSP	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Stichting Pierre Robin Europe	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
The Bardo Foundation	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
The European Registries for Rare Endocrine and Bone Conditions	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
TransplantChild	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
United Japanese Researchers Around the world: UJA	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Universidade de Trás-os-Montes e Alto Douro	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
Università cattolica SCUORE	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
University Children Hospital Cracow	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
University College Dublin	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
University Hospital of Aachen	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
University Hospital of Graz, Austria	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
UZ Leuven - KULeuven	ERN representatives/ academics / healthcare professionals/ researchers / research foundations / medical student
UNICANCER	Federation of comprehensive cancer centers UNICANCER
admedicum	Healthcare industry / commercial companies / consultants / investors
admedicum GmbH & Co KG	Healthcare industry / commercial companies / consultants / investors
Akums Drugs and Pharmaceuticals	Healthcare industry / commercial companies / consultants / investors

alexion	Healthcare industry / commercial companies / consultants / investors
AOP Orphan Pharmaceuticals GmbH	Healthcare industry / commercial companies / consultants / investors
AOP Orphan Pharmaceuticals GmbHJ	Healthcare industry / commercial companies / consultants / investors
as we know	Healthcare industry / commercial companies / consultants / investors
Association of Innovative Pharmaceutical Industry	Healthcare industry / commercial companies / consultants / investors
ATMOSR	Healthcare industry / commercial companies / consultants / investors
Azafaros	Healthcare industry / commercial companies / consultants / investors
Biogen	Healthcare industry / commercial companies / consultants / investors
Blueprint Medicines	Healthcare industry / commercial companies / consultants / investors
Chiesi	Healthcare industry / commercial companies / consultants / investors
Chiesi Benelux	Healthcare industry / commercial companies / consultants / investors
Chiesi GmbH	Healthcare industry / commercial companies / consultants / investors
Chiesi Rare Diseases	Healthcare industry / commercial companies / consultants / investors
CSL Behring	Healthcare industry / commercial companies / consultants / investors
DGA Group	Healthcare industry / commercial companies / consultants / investors
DHC Technologies	Healthcare industry / commercial companies / consultants / investors
Digital Content	Healthcare industry / commercial companies / consultants / investors
Dolon Ltd	Healthcare industry / commercial companies / consultants / investors
EFPIA	Healthcare industry / commercial companies / consultants / investors
Egetis Therapeutics AB	Healthcare industry / commercial companies / consultants / investors
EuropaBio	Healthcare industry / commercial companies / consultants / investors
Humanized Solutions	Healthcare industry / commercial companies / consultants / investors
IDEA Regulatory	Healthcare industry / commercial companies / consultants / investors
Incyte	Healthcare industry / commercial companies / consultants / investors

NER Medical Research Consulting	Healthcare industry / commercial companies / consultants / investors
Neuro-Informed Ltd	Healthcare industry / commercial companies / consultants / investors
one2treat	Healthcare industry / commercial companies / consultants / investors
Orchard Therapeutics	Healthcare industry / commercial companies / consultants / investors
Orphan Now	Healthcare industry / commercial companies / consultants / investors
Premier Research	Healthcare industry / commercial companies / consultants / investors
Rare Care Centre, Perth Children's Hospital	Healthcare industry / commercial companies / consultants / investors
Sanofi	Healthcare industry / commercial companies / consultants / investors
Swixx Biopharma	Healthcare industry / commercial companies / consultants / investors
Terrapinn	Healthcare industry / commercial companies / consultants / investors
UCB	Healthcare industry / commercial companies / consultants / investors
WDLBio Ltd	Healthcare industry / commercial companies / consultants / investors
RARE Revolution Magazine	Media company elevating voice of PLWRD.
Together for Rare Diseases	Multi-stakeholder group
TRANSFORM, European Alliance for Transformative Therapies	Multi-stakeholder initiative
OrphanHealthcare	NGO, support, guidance, literacy, coaching, direct help
TEDDY - European Network of Excellence for Paediatric Clinical Research	Not for profit Research Association
FHSD SPAIN	Patient affected rare disease FHSD
A.M.M.I	particular
22q11 Ireland	Patient advocate / patient organisation
22q11europe	Patient advocate / patient organisation
95 Rare Alliance Greece	Patient advocate / patient organisation
A Different Story	Patient advocate / patient organisation
A M M I	Patient advocate / patient organisation
A-NCL (Italian Ass Batten Disease)	Patient advocate / patient organisation
A.c.a.r. aps	Patient advocate / patient organisation
A.M.Mi Association against mitochondrial diseases	Patient advocate / patient organisation
AADIC (heart failure patient association)	Patient advocate / patient organisation
ABEFAO	Patient advocate / patient organisation
ABMM	Patient advocate / patient organisation

Acanthamoeba Keratitis Eye Foundation	Patient advocate / patient organisation
Acar	Patient advocate / patient organisation
ACAR Associazione Conto Alla Rovescia	Patient advocate / patient organisation
Achalasie-Selbsthilfe e.V.	Patient advocate / patient organisation
ACMIM- My Child My Heart Association	Patient advocate / patient organisation
ACMT-Rete per la malattia di Charcot-Marie-Tooth OdV	Patient advocate / patient organisation
Adcum - association of urea and metabolic cycle disorders Peru	Patient advocate / patient organisation
Addison Foreningen i Danmark	Patient advocate / patient organisation
Adrenal Society Belgium	Patient advocate / patient organisation
AESCOV	Patient advocate / patient organisation
agencia hht	Patient advocate / patient organisation
AGORA	Patient advocate / patient organisation
Ai vips ets	Patient advocate / patient organisation
AIBWS ODV	Patient advocate / patient organisation
AICCA	Patient advocate / patient organisation
AICI	Patient advocate / patient organisation
Aima-Child aps	Patient advocate / patient organisation
AIMAR	Patient advocate / patient organisation
AINMO	Patient advocate / patient organisation
AIPIT aps	Patient advocate / patient organisation
AIRETT	Patient advocate / patient organisation
AIRP	Patient advocate / patient organisation
AISAC ODV	Patient advocate / patient organisation
AISJAC	Patient advocate / patient organisation
AISMME ASSOCIAZIONE ITALIANA SOSTEGNO MALATTIE METABOLICHE EREDITARIE APS	Patient advocate / patient organisation
AKABE (Assoc.KAbuki Belgium)	Patient advocate / patient organisation
AKU Society	Patient advocate / patient organisation
ALAN Maladies Rares Luxembourg	Patient advocate / patient organisation
Albi España	Patient advocate / patient organisation
Alex, The Leukodystrophy Charity	Patient advocate / patient organisation
Alfa-1 Denmark	Patient advocate / patient organisation
Alianta Nationala Pentru Boli Rare Romania CUI 22874753	Patient advocate / patient organisation
Alliance For Cryoglobulinemia	Patient advocate / patient organisation
Alliance for Pulmonary Hypertension	Patient advocate / patient organisation
ALN a.s.b.l. Maladies Rares Luxembourg	Patient advocate / patient organisation
ALS Liga Belgium	Patient advocate / patient organisation
Alstrom Syndrome UK	Patient advocate / patient organisation
AMC - Artrogriposis Múltiple Congénita	Patient advocate / patient organisation
AMEM France	Patient advocate / patient organisation
Amici Contro la Sarcoidosi Italia ets	Patient advocate / patient organisation

AMIS FSH	Patient advocate / patient organisation
AMMEC-Associazione Malattie Metaboliche Congenite ODV	Patient advocate / patient organisation
AMMeC. Italian Association for Rare Diseases	Patient advocate / patient organisation
AMMI	Patient advocate / patient organisation
AmyBel	Patient advocate / patient organisation
ANDO Portugal	Patient advocate / patient organisation
ANGEL Portugal	Patient advocate / patient organisation
Angelman CZ	Patient advocate / patient organisation
Angelman eV	Patient advocate / patient organisation
Angelman Verein Österreich	Patient advocate / patient organisation
Angioedema Belgium	Patient advocate / patient organisation
ANGP- National Ass. Of Paediatric Glaucoma	Patient advocate / patient organisation
AOI	Patient advocate / patient organisation
APAHE Associação Portuguesa de Ataxias Hereditárias	Patient advocate / patient organisation
APIR	Patient advocate / patient organisation
APN - Associação Portuguesa de Neuromusculares	Patient advocate / patient organisation
APORMast, Associação Portuguesa de Doentes com Mastocitose e Doenças Mastocitárias	Patient advocate / patient organisation
APPW -ASSOCIAÇÃO PORTUGUESA DE PRADERWILLI	Patient advocate / patient organisation
APS FAMIGLIE SYNGAP1 ITALIA	Patient advocate / patient organisation
ARMONIA	Patient advocate / patient organisation
ARPID	Patient advocate / patient organisation
Arthur's Quest & SLC6A1 Connect UK	Patient advocate / patient organisation
ARVC-Selbsthilfe e.V.	Patient advocate / patient organisation
ASBI Italy	Patient advocate / patient organisation
ASMD España	Patient advocate / patient organisation
Asociace muskulárních dystrofičků v ČR	Patient advocate / patient organisation
Asociacia polio v SR / Slovak Polio Association	Patient advocate / patient organisation
Asociácia Vaskulárnych Kompresívnych Syndrómov a Ehlers-Danlos, o.z.	Patient advocate / patient organisation
Asociación Corea de Huntington de Castilla y León	Patient advocate / patient organisation
ASOCIACION COREA DE HUNTINGTON ESPAÑOLA - ACHE	Patient advocate / patient organisation
Asociación CTNNB1	Patient advocate / patient organisation
Asociación DDX3X España	Patient advocate / patient organisation
Asociación Española de Deficit de Lipasa Acida Lisosomal (AELALD)	Patient advocate / patient organisation
Asociación Española de Paraparesia Espástica Familiar- AEPEF	Patient advocate / patient organisation

Asociación Gaucher de México	Patient advocate / patient organisation
Asociacion HHT ESOAÑA	Patient advocate / patient organisation
Asociación Kleefstra España	Patient advocate / patient organisation
Asociacion SAMS, Spain	Patient advocate / patient organisation
asociacion sindrome persona rigida - stiffperson-	Patient advocate / patient organisation
Asociatia Andreas-Rares	Patient advocate / patient organisation
Asociația Children's Joy	Patient advocate / patient organisation
Asociatia Daruieste Speranta Distrofie Musculara	Patient advocate / patient organisation
Asociatia de Scleroza Multipla Bucuresti	Patient advocate / patient organisation
Asociatia Distroficilor Muscular din Romania	Patient advocate / patient organisation
Asociația Glut1 Rebe&Luca	Patient advocate / patient organisation
Asociatia Nationala Miastenia Gravis Romania (RoMGA)	Patient advocate / patient organisation
Asociația Oamenilor mici	Patient advocate / patient organisation
Asociația Pacienților cu Boala Fabry din România	Patient advocate / patient organisation
Asociația Pacienților cu Sindrom Hemolitic Uremic din România	Patient advocate / patient organisation
Asociația Pacienților cu Tumori Neuroendocrine din Romania	Patient advocate / patient organisation
Asociația Pentru Matei	Patient advocate / patient organisation
Asociatia Persoanelor cu Glicogenoza	Patient advocate / patient organisation
Asociația Pku Life România	Patient advocate / patient organisation
Asociația Prader Willi din România	Patient advocate / patient organisation
Asociația Prader-Willi București	Patient advocate / patient organisation
Asociația Română de Cancere Rare	Patient advocate / patient organisation
Asociatia Smiling Faces Romania	Patient advocate / patient organisation
Associação Nacional de Fibrose Quística	Patient advocate / patient organisation
Associação PXE Portugal	Patient advocate / patient organisation
Associação Sanfilippo Portugal	Patient advocate / patient organisation
Associació Catalana de Malalts de Huntington - ACMAH	Patient advocate / patient organisation
Associació Catalana de Malalts de Huntington (ACMAH)	Patient advocate / patient organisation
Association A.M.Mi	Patient advocate / patient organisation
Association AGM	Patient advocate / patient organisation
Association Anémie Dysérythroïétique Congénitale	Patient advocate / patient organisation
Association Bernard Pépin pour la maladie de Wilson	Patient advocate / patient organisation
Association contre les maladies mitochondriales	Patient advocate / patient organisation

Association d'aide aux Personnes Epileptiques AAPE	Patient advocate / patient organisation
Association des Patients Sclérodermiques de Belgique	Patient advocate / patient organisation
Association Enfants CASK France	Patient advocate / patient organisation
Association GÉNÉRATION 22	Patient advocate / patient organisation
Association HTaPFrance	Patient advocate / patient organisation
Association Marfans	Patient advocate / patient organisation
Association MNT Mon Poumon Mon Air	Patient advocate / patient organisation
Association Noonan	Patient advocate / patient organisation
Association of citizens for rare diseases LIFE WITH CHALLENGES	Patient advocate / patient organisation
Association of Families with Angelman Syndrome	Patient advocate / patient organisation
Association of patients with blood diseases of Slovenia	Patient advocate / patient organisation
Association Ollier Maffucci	Patient advocate / patient organisation
Association pour la Lutte Contre l'Alcaptonurie - ALCAP	Patient advocate / patient organisation
associazione italiana glicogenosi	Patient advocate / patient organisation
Associazione Italiana GLUT1	Patient advocate / patient organisation
Associazione Italiana HHT Onilde Carini APS	Patient advocate / patient organisation
Associazione Italiana Niemann Pick ONLUS	Patient advocate / patient organisation
Associazione Italiana sindrome ADNP	Patient advocate / patient organisation
Associazione Ligure Thalassefici OdV	Patient advocate / patient organisation
Associazione Nazionale Persone con Malattie Reumatologiche e Rare APS ETS	Patient advocate / patient organisation
AVLT	Patient advocate / patient organisation
AVMinority, z.s.	Patient advocate / patient organisation
Bag3 Research Foundation	Patient advocate / patient organisation
Behcet's UK	Patient advocate / patient organisation
BePoPi	Patient advocate / patient organisation
Bindweefsel.be - Vlaamse Vereniging voor Erfelijke	Patient advocate / patient organisation
BOKS vzw	Patient advocate / patient organisation
Brittle Bone Society (BBS)	Patient advocate / patient organisation
Bulgarian society of the patients with PH	Patient advocate / patient organisation
Bulgarian TTP Association	Patient advocate / patient organisation
Bundesverband für PFFD, FFU, Fibula- und Tibiadeфекte e.V.	Patient advocate / patient organisation
Bundesverband Niere	Patient advocate / patient organisation
Bundesverband Williams-Beuren-Syndrom e.v.	Patient advocate / patient organisation
Butterfly Bone Health Society	Patient advocate / patient organisation

Butterfly è metamorphosis, la cultura per il sociale APS	Patient advocate / patient organisation
CardioGen	Patient advocate / patient organisation
Cchs Israel- yad la neshima	Patient advocate / patient organisation
CCI Europe	Patient advocate / patient organisation
CFD Foundation	Patient advocate / patient organisation
CFSME Associazione Italiana odv	Patient advocate / patient organisation
CHAMP1 Foundation - Europe	Patient advocate / patient organisation
CHAMP1 UK	Patient advocate / patient organisation
Child	Patient advocate / patient organisation
Child and Youth Care Zimbabwe	Patient advocate / patient organisation
Chilgren with SMA, Foundation	Patient advocate / patient organisation
CIB-liga vzw	Patient advocate / patient organisation
Cistinosi Italia ODV	Patient advocate / patient organisation
CMP Vllanderen vzw	Patient advocate / patient organisation
CMTC-OVM (global non-profit) for patients with vascular malformationd, their families and healthcare professionals	Patient advocate / patient organisation
CMTUK	Patient advocate / patient organisation
Cometa ASMME - Associazione Studio Malattie Metaboliche Ereditarie	Patient advocate / patient organisation
Community And Family Aid Foundation-Ghana	Patient advocate / patient organisation
Conquistando Escalones ODV	Patient advocate / patient organisation
Croatian rare liver foundation	Patient advocate / patient organisation
Cure & Action for Tay-Sachs (CATS) Foundation	Patient advocate / patient organisation
Cutis Laxa Internationale	Patient advocate / patient organisation
Cylper	Patient advocate / patient organisation
Cyprus Alliance for Rare Disorders	Patient advocate / patient organisation
Cyprus Huntington's Disease Association	Patient advocate / patient organisation
Cyprus Pulmonary Association	Patient advocate / patient organisation
Cystische Fibrose Hilfe Oberösterreich	Patient advocate / patient organisation
D'Genes Asociación	Patient advocate / patient organisation
Danish Association of Fabry Patients	Patient advocate / patient organisation
Debra Belgium	Patient advocate / patient organisation
Debra Croatia	Patient advocate / patient organisation
DEBRA FRANCE	Patient advocate / patient organisation
DEBRA International	Patient advocate / patient organisation
Debra Ireland.	Patient advocate / patient organisation
Debra Serbia	Patient advocate / patient organisation
DEBRA Spain	Patient advocate / patient organisation
Deutsche Sarkoidose-Vereinigung e.V.	Patient advocate / patient organisation

Disorder of the Corpus Callosum Hungary Foundation	Patient advocate / patient organisation
DMD Aileleri Derneği/Türkiye	Patient advocate / patient organisation
DMD CARE Association	Patient advocate / patient organisation
DOCE	Patient advocate / patient organisation
Dravet Syndrome Croatia	Patient advocate / patient organisation
Dravet Syndrome Foundation Spain (Fundación Síndrome de Dravet)	Patient advocate / patient organisation
Duchenne Data Foundation	Patient advocate / patient organisation
Duchenne Hungary	Patient advocate / patient organisation
Duchenne Parent Project Spain	Patient advocate / patient organisation
dutch federation of cancer patient organisations	Patient advocate / patient organisation
Dutch Pituitary Foundation	Patient advocate / patient organisation
DysNet - Dysmelia Network	Patient advocate / patient organisation
Dystonia Europe	Patient advocate / patient organisation
EAT Esophageal Atresia Global Support Groups	Patient advocate / patient organisation
ECMTF	Patient advocate / patient organisation
EDS Lëtzebuerg a.s.b.l.	Patient advocate / patient organisation
Een Häerz fir kriibskrank Kanner asbl	Patient advocate / patient organisation
Empowered By Us	Patient advocate / patient organisation
EOS Network - Eosinophilic Diseases Charity	Patient advocate / patient organisation
EPODIN	Patient advocate / patient organisation
ESPERANTRA	Patient advocate / patient organisation
Espoir de Noisette	Patient advocate / patient organisation
EuroHSP	Patient advocate / patient organisation
European children's hospitals organisation	Patient advocate / patient organisation
European Chromosome 11 Network	Patient advocate / patient organisation
European CMT Federation	Patient advocate / patient organisation
European Foundation for SATB2-Associated Syndrome	Patient advocate / patient organisation
European Haemophilia Consortium	Patient advocate / patient organisation
European Huntington Association	Patient advocate / patient organisation
European Huntington's Disease Association	Patient advocate / patient organisation
European Lung Foundation	Patient advocate / patient organisation
European MEN Alliance e.V.	Patient advocate / patient organisation
European Pulmonary Fibrosis Federation	Patient advocate / patient organisation
FAST Poland	Patient advocate / patient organisation
FB Group: Got Diabetes Insipidus/AVP-D/AVP-R?	Patient advocate / patient organisation
Federacion Española de Enfermedades Raras	Patient advocate / patient organisation
Federación Española de Padres de Niños con Cáncer	Patient advocate / patient organisation

federg	Patient advocate / patient organisation
federg, ERKNet ePAG Chair	Patient advocate / patient organisation
FEDRA	Patient advocate / patient organisation
FH Europe Foundation	Patient advocate / patient organisation
Flutters and Strutters	Patient advocate / patient organisation
Folkhälsan	Patient advocate / patient organisation
Fondatioun Kriibskrank Kanner	Patient advocate / patient organisation
Fondazione Alessandra Bisceglia ViVa Ale ETS	Patient advocate / patient organisation
FOP e.V.	Patient advocate / patient organisation
FOP Friends	Patient advocate / patient organisation
Fop Italia odv	Patient advocate / patient organisation
Foreningen for sjeldne nevroutviklingsforstyrrelse	Patient advocate / patient organisation
Foundation for Angelman Syndrome Therapeutics	Patient advocate / patient organisation
Foundation of Borys the Hero	Patient advocate / patient organisation
Fragile X International	Patient advocate / patient organisation
French fragile x	Patient advocate / patient organisation
Frieda, z.s.	Patient advocate / patient organisation
FSHD Finland	Patient advocate / patient organisation
Fshd Italia aps	Patient advocate / patient organisation
Fundacja Sanfilippo	Patient advocate / patient organisation
GBS-CIDP Foundation International	Patient advocate / patient organisation
Genetic Alliance Australia	Patient advocate / patient organisation
Genetic Alliance UK	Patient advocate / patient organisation
Georgian Foundation for Genetic and Rare Diseases	Patient advocate / patient organisation
Georgian Rett syndrome and other rare diseases association	Patient advocate / patient organisation
Ges. für MukoPolySaccharidosen und ähnliche Erkrankungen	Patient advocate / patient organisation
GESED asbl - Groupe d'entraide des Syndromes d'Ehlers-Danlos	Patient advocate / patient organisation
Gitelbart association	Patient advocate / patient organisation
Glandula Hypophysen- und Nebennierenerkrankungen e.V.	Patient advocate / patient organisation
Gli Equilibristi HIBM	Patient advocate / patient organisation
Gli Equilibristi HIBM APS	Patient advocate / patient organisation
Global Genes	Patient advocate / patient organisation
GNAO1 España	Patient advocate / patient organisation
GRIN Europe	Patient advocate / patient organisation
HAE patiënt organisation	Patient advocate / patient organisation
Healthcare Education Institute	Patient advocate / patient organisation

Hellenic Community for Pulmonary Hypertension	Patient advocate / patient organisation
Hellenic Cystic Fibrosis Association	Patient advocate / patient organisation
HELLENIC LEAGUE AGAINST RHEUMATISM	Patient advocate / patient organisation
Hepar Centar Bitola	Patient advocate / patient organisation
Hereditary Brain Aneurysm Support	Patient advocate / patient organisation
HHT Ireland	Patient advocate / patient organisation
HHT Sverige	Patient advocate / patient organisation
HHT Sweden	Patient advocate / patient organisation
hipofam	Patient advocate / patient organisation
HomeCare Association/Hope Support Group	Patient advocate / patient organisation
HTAP BELGIQUE	Patient advocate / patient organisation
HTAP Belgique asbl	Patient advocate / patient organisation
HUFERDIS	Patient advocate / patient organisation
Hungarian Organisation for Patients with Immunodeficiency (HOPI)	Patient advocate / patient organisation
Hungarian Organisation for Primary Immunodeficiencies	Patient advocate / patient organisation
Hungarian Porphyria Organisation	Patient advocate / patient organisation
HUNTINGTON LIGA vzw	Patient advocate / patient organisation
Huntington's Disease Association of Ireland	Patient advocate / patient organisation
Huntingtons disease	Patient advocate / patient organisation
HWSA	Patient advocate / patient organisation
IDefine Europe Foundation	Patient advocate / patient organisation
Inima copiilor	Patient advocate / patient organisation
INSTITUTO VIDAS RARAS	Patient advocate / patient organisation
International Gaucher Alliance	Patient advocate / patient organisation
International NGO Dermatologists for Children (DEBRA UKRAINE)	Patient advocate / patient organisation
International Pemphigus & Pemphigoid Foundation	Patient advocate / patient organisation
International Pemphigus and Pemphigoid Foundation	Patient advocate / patient organisation
International Prader-Willi Syndrome Organisation	Patient advocate / patient organisation
Irish Lung Fibrosis Association	Patient advocate / patient organisation
Italian Gaucher Association	Patient advocate / patient organisation
Italian Gaucher Association ODV	Patient advocate / patient organisation
ITP Support Association	Patient advocate / patient organisation
K.i.s.E Kinder in schwieriger Ernährungssituation e. V.	Patient advocate / patient organisation
Karkinaki	Patient advocate / patient organisation
KBG Syndrome Association	Patient advocate / patient organisation
Khmelnyskyi OMNI-center for Children Development	Patient advocate / patient organisation

Klinefelter's Syndrome Association	Patient advocate / patient organisation
Krajowe Forum Orphan Poland	Patient advocate / patient organisation
KRIKOS ZOIS	Patient advocate / patient organisation
LAMA2 France	Patient advocate / patient organisation
Landsforeningen Multipel System Atrofi	Patient advocate / patient organisation
LAPOSA	Patient advocate / patient organisation
Idlgreece	Patient advocate / patient organisation
Lega Italiana Sclerosi Sistemica	Patient advocate / patient organisation
Let's Cure ACC	Patient advocate / patient organisation
Leukämiehilfe RHEIN-MAIN e. V.	Patient advocate / patient organisation
Leukämiehilfe RHEIN-MAIN e.V.	Patient advocate / patient organisation
Leven met acromegalie	Patient advocate / patient organisation
Ligue Huntington Francophone Belge LHFB	Patient advocate / patient organisation
Lithuanian association of people with genetic NMD Sraunija	Patient advocate / patient organisation
Lithuanian multiple sclerosis union	Patient advocate / patient organisation
LMCRO	Patient advocate / patient organisation
LMNA Cardiac	Patient advocate / patient organisation
LMNA cardiac foundation	Patient advocate / patient organisation
LMNACardiac	Patient advocate / patient organisation
LPCDR (Portuguese League Against Rheumatic Diseases)	Patient advocate / patient organisation
Lymphido ODV	Patient advocate / patient organisation
Magyarországi Immunhiányos Betegek Egyesülete	Patient advocate / patient organisation
MaRaVaud	Patient advocate / patient organisation
Marfanhilfe Deutschland e.V.	Patient advocate / patient organisation
MasVisibles	Patient advocate / patient organisation
Matio Fundacja Pomocy Rodzinom i Chorym Na Mukowiscydozę	Patient advocate / patient organisation
MATIO Polish CF Foundation	Patient advocate / patient organisation
MCT8-AHDS Foundation	Patient advocate / patient organisation
META, z.s.	Patient advocate / patient organisation
METODĚJ z.s.	Patient advocate / patient organisation
MOG	Patient advocate / patient organisation
MPS Társaság	Patient advocate / patient organisation
Mpsturk	Patient advocate / patient organisation
Myelitis e.V.	Patient advocate / patient organisation
Myeloma Patients Europe	Patient advocate / patient organisation
MYMU WALLONIE-BRUXELLES ASBL	Patient advocate / patient organisation
NAnA ETS	Patient advocate / patient organisation
National Alliance for Rare Diseases Support - Malta	Patient advocate / patient organisation

National Alliance for Rare Diseases Support Malta	Patient advocate / patient organisation
National Alliance of People with Rare Diseases - Bulgaria	Patient advocate / patient organisation
National Association for PKU and other IEM Czech Republic	Patient advocate / patient organisation
National association of patients with mitochondrial diseases, Bulgaria	Patient advocate / patient organisation
National Association of Porphyrrias Serbia	Patient advocate / patient organisation
National Forum Orphan Poland	Patient advocate / patient organisation
National Gaucher Organization in Bulgaria	Patient advocate / patient organisation
NBIA Suisse	Patient advocate / patient organisation
Nessuno è Escluso	Patient advocate / patient organisation
Netzwerk für Hypophysen- und Nebennierenerkrankungen e. V.	Patient advocate / patient organisation
Netzwerk Hypophysen und Nebennierenerkrankungen e.V.	Patient advocate / patient organisation
Neuro Move CMT Association	Patient advocate / patient organisation
Neuropatias Autoinmunes- GBS CIDP España	Patient advocate / patient organisation
NF Kinder	Patient advocate / patient organisation
NFVN (Dutch patient organization)	Patient advocate / patient organisation
NGO KARKINAKI AWARENESS FOR CHILDHOOD AN	Patient advocate / patient organisation
Niemann-Pick UK	Patient advocate / patient organisation
NMP Belgique asbl	Patient advocate / patient organisation
Norwegian Osteogenesis Imperfecta Association	Patient advocate / patient organisation
NVACP Adrenal benelux	Patient advocate / patient organisation
NVSP	Patient advocate / patient organisation
Omirge Sen (believe in life) public foundation	Patient advocate / patient organisation
Osteogenesis Imperfecta Federation Europe	Patient advocate / patient organisation
PACS2 Research Foundation	Patient advocate / patient organisation
Panhellenic Association of Patients and Friends of Lysosomal Diseases "Solidarity"	Patient advocate / patient organisation
Panhellenic Association of Patients and friends suffering from Lysosomal Diseases "the Solidarity"	Patient advocate / patient organisation
PANHELLENIC HEART DISEASE ASSOCIATION	Patient advocate / patient organisation
Pans Pandas Italia APS	Patient advocate / patient organisation
PARENT PROJECT Czech Republic	Patient advocate / patient organisation
Parent Project Romania	Patient advocate / patient organisation
PCH-Familie e.V.	Patient advocate / patient organisation
Pemphigus und Pemphigoid Selbsthilfegruppe e.V. Germany	Patient advocate / patient organisation
Petit Coeur de Beurre	Patient advocate / patient organisation

PH Association the Netherlands	Patient advocate / patient organisation
PHA Europe	Patient advocate / patient organisation
PHeV Germany	Patient advocate / patient organisation
PIP-UK Poland Syndrome Support and Network	Patient advocate / patient organisation
Pks Italia APS	Patient advocate / patient organisation
Pks italia onlus	Patient advocate / patient organisation
PksItalia Ape	Patient advocate / patient organisation
Plućna hipertenzija Srbija (PH Serbia))	Patient advocate / patient organisation
PNH Ukraine	Patient advocate / patient organisation
PO"UAP PKU "Special children"	Patient advocate / patient organisation
Pompe Disease	Patient advocate / patient organisation
Pompe Support Network	Patient advocate / patient organisation
Portuguese Huntington Association	Patient advocate / patient organisation
Prader-Willi Syndrome Hellas	Patient advocate / patient organisation
Primer Immunhiányos Betegek Egyesülete	Patient advocate / patient organisation
Pro Rare Austria	Patient advocate / patient organisation
Pulmonary Hypertension Ukrainian Rare Disease Association-PHURDA	Patient advocate / patient organisation
RaDiOrg - Rare Diseases Belgium	Patient advocate / patient organisation
Raramente, CRL	Patient advocate / patient organisation
Rare Disease Hong Kong	Patient advocate / patient organisation
Rare disease, Sweden	Patient advocate / patient organisation
Rare Diseases Bulgaria	Patient advocate / patient organisation
Rare Diseases Czech Republic	Patient advocate / patient organisation
RARE DISEASES GREECE (RDG)	Patient advocate / patient organisation
Rare Diseases International	Patient advocate / patient organisation
Rare Diseases Ireland	Patient advocate / patient organisation
Rare Diseases Society Nepal	Patient advocate / patient organisation
Rare Diseases Sweden	Patient advocate / patient organisation
RD-PORTUGAL (RARE DISEASES)	Patient advocate / patient organisation
Relais 22	Patient advocate / patient organisation
Respiratory failure and lung transplantation association	Patient advocate / patient organisation
Retina Bulgaria	Patient advocate / patient organisation
RetinaPigmentosa	Patient advocate / patient organisation
Revma Liga Česká Republika z.s	Patient advocate / patient organisation
Riksföreningen Alfa-1 Sverige	Patient advocate / patient organisation
RIROSZ Hungary	Patient advocate / patient organisation
Romanian Association for patients with peripheral immune polyneuropathy	Patient advocate / patient organisation
Romanian Hemophilia Association	Patient advocate / patient organisation
Romanian Prader Willi Association, RONARD	Patient advocate / patient organisation
Rotary Club of World Disability Advocacy	Patient advocate / patient organisation

SAF España	Patient advocate / patient organisation
salivary gland cancer uk	Patient advocate / patient organisation
Sällsynta diagnoser	Patient advocate / patient organisation
SAMS Asociacion, Síndromes arrítmicos relacionados con la muerte súbita	Patient advocate / patient organisation
Sanfilippo Fighters APS	Patient advocate / patient organisation
Sanfilippo Initiative e.V.	Patient advocate / patient organisation
Sang pour sang	Patient advocate / patient organisation
Sarkoidose-Netzwerk e.V.	Patient advocate / patient organisation
SCN2A Georgian Association	Patient advocate / patient organisation
Scn8a Italia ODV	Patient advocate / patient organisation
Sdružení pacientů s plicní hypertenzí, z.s.	Patient advocate / patient organisation
Sjögren Europe	Patient advocate / patient organisation
SMA Europe	Patient advocate / patient organisation
Society of Pulmonary Hypertension (Latvia)	Patient advocate / patient organisation
SoMA e.V.	Patient advocate / patient organisation
Spastic Paraplegia Foundation	Patient advocate / patient organisation
Spierziekten Nederland	Patient advocate / patient organisation
Spolek pro Atypické Parkinsonské Syndromy	Patient advocate / patient organisation
Spolek Řasinka	Patient advocate / patient organisation
Srdickari (www.srdickari.cz)	Patient advocate / patient organisation
Stargard's Connected	Patient advocate / patient organisation
Stargardt's Connected	Patient advocate / patient organisation
Stichting IJzersterk	Patient advocate / patient organisation
Stichting Platform CADASIL	Patient advocate / patient organisation
Stichting Ushersyndroom - www.ushersyndroom.nl	Patient advocate / patient organisation
Stichting Vasculitis International	Patient advocate / patient organisation
Stichting Voor Sara	Patient advocate / patient organisation
Stichting Zeldzame Bloedziekten	Patient advocate / patient organisation
Stickler Norge	Patient advocate / patient organisation
Stiftung lichterzellen	Patient advocate / patient organisation
stopp-HSP	Patient advocate / patient organisation
Swedish Cystic Fibrosis Association	Patient advocate / patient organisation
Swedish Network against Cancer	Patient advocate / patient organisation
Syngap Elternhilfe e.V.	Patient advocate / patient organisation
The Children's Hyperinsulinism Charity UK and Ireland	Patient advocate / patient organisation
The coalition for rare diseases - Israel	Patient advocate / patient organisation
The Ehlers-Danlos Society	Patient advocate / patient organisation
The Lily Foundation	Patient advocate / patient organisation
The Norrie Disease Foundation	Patient advocate / patient organisation
The Spina Bifida & Hydrocephalus Paediatric Advocacy Group Ireland	Patient advocate / patient organisation

The Wilson Patient Association Denmark	Patient advocate / patient organisation
Thyroid Federation international	Patient advocate / patient organisation
Together Fighting Sarcoma	Patient advocate / patient organisation
Tuberous Sclerosis Complex Ireland	Patient advocate / patient organisation
UNIAMO – Federazione Italiana Malattie Rare	Patient advocate / patient organisation
Unione Italiana Nexmif	Patient advocate / patient organisation
Unione Trapiantati Polmone - Padova ODV	Patient advocate / patient organisation
Unique - rare chromosome and gene disorder support group	Patient advocate / patient organisation
Uniti per la PIPO	Patient advocate / patient organisation
VASCAPA	Patient advocate / patient organisation
Vasculitis Ireland Awareness	Patient advocate / patient organisation
Vereniging van Huntington	Patient advocate / patient organisation
Vereniging voor Angio Oedeem	Patient advocate / patient organisation
Vereniging voor Angio-oedeem/HAE the Netherlands	Patient advocate / patient organisation
Vietnamese Organization for Rare Diseases	Patient advocate / patient organisation
Vivre sans Thyroïde	Patient advocate / patient organisation
Vlaamse Parkinson Liga vzw	Patient advocate / patient organisation
VOKS	Patient advocate / patient organisation
VSOP	Patient advocate / patient organisation
vzw NET&MEN Kanker België	Patient advocate / patient organisation
vzw Overdruksyndroom en Tarlov cysten	Patient advocate / patient organisation
Warrior Gab &Co, donne ton énergie au gène mtND5	Patient advocate / patient organisation
Werdnig Hoffman Association	Patient advocate / patient organisation
WFIPP	Patient advocate / patient organisation
Wilhelm Foundation	Patient advocate / patient organisation
williams sicilia aps	Patient advocate / patient organisation
Wilson Macedonia	Patient advocate / patient organisation
World Alliance of Pituitary Organizations	Patient advocate / patient organisation
www.adtkd.de	Patient advocate / patient organisation
XLH Denmark	Patient advocate / patient organisation
Zebrapad VZW	Patient advocate / patient organisation
ΕΛΛΗΝΙΚΟΣ ΣΥΛΛΟΓΟΣ ΠΝΕΥΜΟΝΙΚΗΣ ΙΝΩΣΗΣ	Patient advocate / patient organisation
Fundación Progreso y Salud	Policy makers/Payer bodies/ HTA agencies/ national competent authorities/ regulators
Health Service Executive	Policy makers/Payer bodies/ HTA agencies/ national competent authorities/ regulators
National Coordination Centre for Rare Diseases - Czech Republic	Policy makers/Payer bodies/ HTA agencies/ national competent authorities/ regulators
Caderno País Positivo	Press
Rare Disease Moonshot	Public-private coalition

RAREvolution Magazine	Rare disease publisher
Zespół Angelmana	Rodzice
Rareminds	Specialist mental health charity
Autoimmune Research & Collaboration Hub (ARCH)	umbrella organisation