

EURORDIS Member Associations - November 2018



| Country | Name | Website | Membership |
|-----------|--|---|------------------|
| Albania | Shoqata e Semundjeve te Rralla - Rare Disease Association | www.rda-al.com | Associate member |
| Algeria | Association ELAMANI pour venir en aide aux malades souffrant de l'anémie héréditaire | | Associate member |
| Argentina | FUNDACION GEISER - GRUPO DE ENLACE, INVESTIGACION Y SOPORTE ENFERMEDADES RARAS | www.fundaciongeiser.org | Associate Member |
| Armenia | Doctors and Children Health Care | | Associate Member |
| Armenia | Neurohereditary Diseases Charity Association | | Associate member |
| Australia | Cystic Fibrosis Australia | www.cysticfibrosis.org.au | Associate member |
| Australia | Genetic Alliance Australia | www.geneticalliance.org.au | Associate member |
| Australia | Rare Voices Australia | www.rarevoices.org.au | Associate member |
| Austria | Angelman Verein Österreich | www.angelman.at | Full member |
| Austria | Debra International | www.debra-international.org | Full member |
| Austria | Hand in Hand für Tay-Sachs & Palliativkinder | www.tay-sachs.net | Associate member |
| Austria | ICA Österreich | www.ica-austria.at | Full member |
| Austria | NF Kinder – Verein zur Förderung der Neurofibromatoseforschung Österreich | www.nfkinder.at | Full member |
| Austria | PH Austria – Initiative Lungenhochdruck | www.lungenhochdruck.at | Full Member |
| Austria | Pro Rare Austria, Allianz für seltenen Erkrankungen | www.prorare-austria.org | Associate member |
| Austria | Pulmonary Hypertension Association Europe | www.phaeurope.org | Associate member |
| Austria | Usher Deafblind Forum Austria | www.usher-taubblind.at | Associate member |
| Belarus | Belarussian Organization of patients with MPS and other rare genetic disorders | http://www.mpssociety.by | Full member |
| Belgium | 22q11 Europe | https://www.facebook.com/22q11europeancongress/ | Associate member |
| Belgium | Alpha-1 Plus asbl | www.alpha1plus.be/ | Associate member |
| Belgium | ALS Liga België | www.alsliga.be | Full member |
| Belgium | Association Belge du Syndrome de Marfan ASBL | www.marfan.be | Full Member |
| Belgium | Association de patients souffrant d'hypertension artérielle pulmonaire en Belgique | http://test.ph-vzw.be/fr_FR/ | Full Member |

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| Belgium | Association pour l'information et la recherche sur les maladies rénales génétiques | http://www.airg-belgique.org | Associate member |
| Belgium | Belgische Organisatie voor Kinderen en Volwassenen met een Stofwisselingsziekte | www.boks.be | Full member |
| Belgium | Belgische Vereniging voor Longfibrose VZW | www.longfibrose.org | Associate member |
| Belgium | be-TSC vzw | http://www.betsc.be | Full member |
| Belgium | CF Europe | www.cf-europe.eu | Full Member |
| Belgium | Contactgroep Myeloom En Waldenström Patiënten | www.cmp-vlaanderen.be | Full member |
| Belgium | Debra Belgium vzw | www.debra-belgium.org | Full member |
| Belgium | Euro Ataxia - European Federation of Hereditary Ataxias | www.euroataxia.org | Full Member |
| Belgium | European Chromosome 11 Network | www.chromosome11.eu | Full Member |
| Belgium | European Haemophilia Consortium | www.ehc.eu | Full Member |
| Belgium | European Network for Research on Alternating Hemiplegia | www.enrah.net | Full Member |
| Belgium | European Polio Union | www.europeanpolio.eu | Full member |
| Belgium | Eye Hope Foundation | www.eyehopefoundation.org | Associate member |
| Belgium | Federation of European Scleroderma Associations | www.fesca-scleroderma.eu | Associate member |
| Belgium | FEDERG - Federation of European associations of patients affected by renal diseases | federg.org | Full member |
| Belgium | FEWS - Federation of European Williams Syndrome | www.eurowilliams.org | Full Member |
| Belgium | HAE Belgium | www.angioedema.be | Associate member |
| Belgium | Ichthyose Belgique - Ichthyosis België | www.ichthyosis.be | Full Member |
| Belgium | International Federation for Spina Bifida and Hydrocephalus | www.ifglobal.org | Full member |
| Belgium | International Huntington Association | www.huntington-assoc.com | Associate member |
| Belgium | Myeloma Patients Europe | www.mpeurope.org | Associate member |
| Belgium | RaDiOrg - Rare Disease Organisation Belgium | www.radiorg.be | Full member |
| Belgium | Rare Disorders Belgium | www.rd-b.be | Associate Member |
| Belgium | Relais 22 asbl | www.relais22.be | Full Member |
| Belgium | SIOP Europe - European Society for Paediatric Oncology | www.siope.eu | Associate member |
| Belgium | Spierziekten Vlaanderen vzw | https://spierziektenvlaanderen.be | Full Member |
| Belgium | Vascular Anomaly Patient Association | www.vascapa.org | Full member |
| Belgium | Vlaams Patiëntenplatform vzw | www.vlaamspatientenplatform.be | Associate member |
| Belgium | Vlaamse Vereniging voor Erfelijke Bindweefselaandoeningen | bindweefsel.be | Full member |
| Benin | Albinos sans frontières | | Associate member |
| Brazil | Associação Brasileira de Enfermedades Raras | http://feberraras.wixsite.com/feber-raras | Associate member |
| Brazil | Associação Brasileira de Paramiloidose | www.paramiloidose.com.br | Associate member |
| Bulgaria | Association of People Suffering by Acromegaly in Bulgaria | www.ababbg.com | Associate member |
| Bulgaria | Bulgarian Anti-Thalassaemic Association | | Full member |
| Bulgaria | Bulgarian Association Wilson Disease | https://wilsonbg.org | Full member |

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| Bulgaria | Bulgarian Cystic Fibrosis Association | http://lifewithcf.org/ | Full member |
| Bulgaria | Bulgarian Huntington Association | http://huntington.bg | Associate member |
| Bulgaria | Information Centre For Rare Diseases And Orphan Drugs | www.raredis.org | Associate Member |
| Bulgaria | NAS - National Association Sarcoidosis Bulgaria | http://sarcoidosisbulgaria.alle.bg/ | Full member |
| Bulgaria | National Alliance of People with Rare Diseases | http://rare-bg.com/ | Associate Member |
| Bulgaria | National Association for Child Support Congenital Hypothyroidism | | Associate member |
| Bulgaria | National Association of the Patients with Growth Hormone Deficiency | https://www.facebook.com/??????????-?????????-??-??????????-?-????????-??-????????-??????-1543573779219269/?fref=hovercard | Full member |
| Bulgaria | National Gaucher Organization | http://gaucher-bg.org/ | Associate member |
| Bulgaria | National Sclerosis Association | http://nasbg.eu | Associate member |
| Bulgaria | National syringomyelia association | | Full member |
| Bulgaria | PHA Bulgaria | www.phabulgaria.eu | Full member |
| Bulgaria | Retina Bulgaria | www.retinabulgaria.bg | Associate member |
| Bulgaria | The Bulgarian Society of Patients with Pulmonary Hypertension | www.bspph.net | Full member |
| Burkina Faso | Fondation Internationale Tierno et Mariam | www.fitima.org | Associate Member |
| Canada | Canadian Organization For Rare Disorders | www.raredisorders.ca | Associate Member |
| Canada | Lymphoma Coalition | http://www.lymphomacoalition.org/ | Associate member |
| Canada | PVNH support & Awareness | www.pvnhsupport.com | Associate member |
| China | Chinese Organization for Rare Disorders | www.hanjianbing.org | Associate member |
| Colombia | Asociación Colombiana de Pacientes con Enfermedades de Depósito Lisosomal | http://www.acopel.org | Associate member |
| Colombia | Foundation Diana Garcia de Olarte for PID | www.fundacion-fip.org | Associate member |
| Croatia | Debra Croatia | www.debra-croatia.com | Full member |
| Croatia | Rare Diseases Croatia | www.rijetke-bolesti.hr | Full member |
| Cyprus | Association of Patients & Friends of IMD "Aspida Zois" | www.aspidazois.com | Full member |
| Cyprus | Cyprus Alliance for Rare Disorders | http://raredisorderscyprus.com/ | Full member |
| Cyprus | Cyprus Primary Immunodeficiency Association and Friends | | Full member |
| Cyprus | Pancyprian Association for Rare Genetic Diseases "Unique Smiles" | www.monadikaxamogela.com | Full member |
| Cyprus | Thalassaemia International Federation (TIF) | www.thalassaemia.org.cy | Full Member |
| Czech Republic | Czech Association of Marfan Syndrome | www.marfanuvsyndrom.websnadno.cz | Associate member |
| Czech Republic | Czech Huntington Association | www.huntington.cz | Associate Member |
| Czech Republic | Klub Nemocnych Cystickou Fibrozou | www.cfklub.cz | Full member |

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| Czech Republic | META, Association of Patients with Lysosomal Storage Diseases | www.sdruzenimeta.cz | Full member |
| Czech Republic | Národní sdružení PKO a jiných DMF (Czech PKO Association) | www.nspku.cz | Full member |
| Czech Republic | Rare diseases Czech Republic (Ceska asociace pro vzacna onemocneni) | www.vzacna-onemocneni.cz | Full member |
| Denmark | 22q11 Danmark | http://www.22q11.dk | Full member |
| Denmark | Addison Foreningen i Danmark | www.addison.dk | Full member |
| Denmark | Blæreekstroforeningens | www.lfmb.dk | Full Member |
| Denmark | CCHS Danmark | http://cchsdanmark.wordpress.com/ | Associate member |
| Denmark | Danish Apert Syndrome Association /Danmarks Apertforening | www.apertforening.dk | Full member |
| Denmark | Danmarks Bloderforening / Danish Haemophilia Society | www.bloderforeningen.dk | Full Member |
| Denmark | Dansk Forening For Neurofibromatosis Recklinghausen | www.nfdanmark.dk | Full member |
| Denmark | Ehlers-Danlos ForeDanmarkningen i | www.ehlers-danlos.dk | Full Member |
| Denmark | Foreningen af Möbiussyndrom i Danmark | www.moebiusyndrom.dk | Full member |
| Denmark | Foreningen for Ataksi / HSP | www.sca-hsp.dk | Full member |
| Denmark | Ichtyosis Association in Denmark | www.iktyosis.dk | Full member |
| Denmark | Immun Defekt Foreningen | www.idf.dk | Full member |
| Denmark | Lupus Europe | www.lupus-europe.org | Associate member |
| Denmark | MCADD-foreningen | www.mcadd.dk | Full member |
| Denmark | Mitokondrie-Foreningen i Danmark | www.mitokondrie.dk/index.php | Full member |
| Denmark | Patientforeningen HAE Danmark | www.hae.dk | Full Member |
| Denmark | Porfyriforeningen Danmark - Porphyria Association Denmark | www.porfyriforeningen.dk | Full Member |
| Denmark | Rare Diseases Denmark (Sjaeldne Diagnoser) | www.sjaeldnediagnoser.dk/ | Full Member |
| Denmark | The Danish association of von Hippel Lindau patients and their relatives | www.vhl.dk | Full member |
| Denmark | The Danish Osteogenesis Imperfecta Society | www.dfoi.dk | Full Member |
| Denmark | Wilson Patientforeningen | www.wilsons.dk | Full member |
| Estonia | Estonian Prader Willi Syndrome Association | www.pws.ee | Full member |
| Finland | Association of Cancer Patients in Finland (Suomen syöpäpotilaat ry,) | www.syopapotilaat.fi | Full member |
| Finland | Finnish Allergy, Skin and Asthma Federation | www.allergia.fi | Full member |
| Finland | Finnish Association for Ultra-rare Diseases | www.ultraharvinaiset.fi | Full member |
| Finland | Finnish Association of People with Physical Disabilities | www.invalidiliitto.fi | Full Member |
| Finland | Finnish Neuro Society | www.ms-liitto.fi | Full Member |
| Finland | HARSO-Rare Disease Alliance Finland | www.harso.fi | Associate member |
| Finland | Harvinaiset-verkosto - Finnish Network for Rare Diseases | www.harvinaiset.fi | Associate member |
| Finland | Inclusion Finland KVTL | www.kvtl.fi | Full Member |

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| Finland | Rinneke Foundation, Norio Centre | www.rinneke.fi | Associate member |
| Finland | Suomen Vaskuliittiyhdistys ry | | Full member |
| France | AFMKT-France | www.associationkystedetarlov.com | Full member |
| France | AFM-Téléthon | www.afm-France.org | Full Member |
| France | Alliance Maladies Rares | www.alliance-maladies-rares.org | Full Member |
| France | Alliance syndrome de Dravet | www.dravet.fr | Full member |
| France | Ass. internationale de dystrophie neuro axonale infantile | http://www.nbiaalliance.org | Full Member |
| France | ASSEDEA | www.assedea.fr | Full member |
| France | Association ISIS | www.isis-asso.com | Full member |
| France | Association "Les Petits Courageux" | www.lesptitscourageux.net | Associate member |
| France | Association AMS-ARAMISE | www.ams-aramise.fr | Full Member |
| France | Association Anémies Dyserythropoïétiques Congénitales | | Full Member |
| France | Association Contre Les Maladies Mitochondriales | www.association-ammi.org | Full Member |
| France | Association Craniopharyngiome Solidarité | www.cranio.fr | Full member |
| France | Association de lutte contre l'arachnoïdite, les douleurs neuropathiques, les pathologies méningées et sacrées et autres maladies orphelines | | Associate member |
| France | Association de Prefiguration de la Fondation Denise Picard | www.fondation-denisepicard.org | Associate member |
| France | Association de Soutien et d'Information à la Leucémie Lymphoïde Chronique et la maladie de Waldenström | www.sillc-asso.org | Full member |
| France | Association des Amis d'Anne-Lorène - Syndrome d'Aicardi | www.aicardi.info | Full Member |
| France | Association Des Groupes Amitié Turner | www.agat-turner.org | Full Member |
| France | Association des Malades du Syndrome de Mccune-Albright | www.assymcal.org | Full Member |
| France | Association des Malades souffrant d'Angio Oedème par déficit en C1 Inhibiteur | www.amsao.fr | Full Member |
| France | Association des Pancréatites Chroniques Héritaires | www.association-apch.org | Full Member |
| France | Association des Patients de La Maladie de Fabry | www.apmf-fabry.org | Associate Member |
| France | Association des Personnes Concernées par le Tremblement Essentiel | www.aptes.org | Associate Member |
| France | Association des POIC | http://www.association-poic.fr/ | Full Member |
| France | Association du Locked-In Syndrome | www.alis-asso.fr | Full Member |
| France | Association du Naevus Géant Congénital | naevus.fr | Full Member |
| France | Association Française contre l'Amylose | www.amylose.asso.fr | Full member |
| France | Association Française de la Fièvre Méditerranéenne Familiale | https://www.affmf.com/ | Full member |
| France | Association Française de la Maladie de Fanconi | www.fanconi.com | Full member |
| France | Association Française de l'Ataxie de Friedreich | www.afaf.asso.fr/ | Full Member |

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| France | Association Française de l'Osteodystrophie Héritaire d'Albright | www.afoha.org | Full member |
| France | Association Française de l'Ostéogenèse Imparfait | www.aoi.asso.fr | Full Member |
| France | Association Française de Narcolepsie-Cataplexie et Hypersomnie | www.anc-narcolepsie.com | Full Member |
| France | Association Française des Dysplasies Ectodermiques | www.afde.net | Full Member |
| France | Association Française des Hémophiles | www.afh.asso.fr | Full Member |
| France | Association Française des Malades Atteints de Porphyries | www.porphyrries-patients.org | Associate member |
| France | Association Française des Maladies Héritaires du Rythme Cardiaque | www.afmhrc.org | Full member |
| France | Association Française des Patients en Auto-Traitement | www.afpat.fr | Associate member |
| France | Association Française Des Syndromes d'Ehlers-Danlos | www.afsed.com | Full Member |
| France | Association Française du Gougerot-Sjögren | www.afgs-syndromes-secs.org | Full Member |
| France | Association Française du Lupus et autres Maladies Auto-Immunes | www.lupusplus.com | Full Member |
| France | Association Française du Syndrome de Cornelia de Lange | http://afscdl.fr | Full member |
| France | Association française du Syndrome de Lowe | www.syndrome-lowe.org | Full member |
| France | Association Française du Syndrome de Rett | www.afsr.net | Full Member |
| France | Association Française du Syndrome d'Ondine | www.afsondine.org | Full Member |
| France | Association Française du Syndrome Phelan-mcdermid | http://22q13.fr | Full member |
| France | Association Française Lesch-Nyhan Action | www.lesch-nyhan-action.org | Full member |
| France | Association Française pour le Syndrome de Gilles de la Tourette | www.france-tourette.org | Full Member |
| France | Association France Vascularites | www.association-vascularites.org | Full member |
| France | Association François Aupetit | www.afa.asso.fr | Associate member |
| France | Association Francophone contre la Polychondrite Chronique Atrophiante | www.afpca.fr | Associate Member |
| France | Association Francophone des Glycogénoses | www.glycogenoses.org | Full Member |
| France | Association Francophone du Syndrome d'Angelman | www.angelman-afsa.org | Full member |
| France | Association Hemochromatose France | www.hemochromatose.fr | Associate member |
| France | Association Histiocytose France | www.histiocytose.org | Full Member |
| France | Association Huntington France | www.huntington.fr | Full Member |
| France | Association Hypoparathyroidisme France | www.hypopara.fr | Full member |
| France | Association Ichtyose France | www.ichtyose.fr | Full member |
| France | Association internationale maladies kystes Tarlov | http://www.aimktarlov.org | Associate member |
| France | Association Kourir | www.kourir.org | Full Member |
| France | Association Maladies Foie Enfants | www.asprehp.org | Full member |

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| France | Association Marfans | www.assomarfans.fr | Full Member |
| France | Association Médicalistes | www.medicalistes.org | Associate member |
| France | Association Microphthalmie France | http://asso-microphthalmie.org | Full member |
| France | Association Naevus 2000 France Europe | www.naevus2000franceeurope.org | Full Member |
| France | Association Nationale des Cardiaques Congénitaux | www.ancc.asso.fr | Full Member |
| France | Association Neurofibromatoses & Recklinghausen | www.anrfrance.fr | Full Member |
| France | Association Ollier Maffucci Europe | www.olliermaffucci-asso.fr | Full member |
| France | Association Pemphigus – Pemphigoïdes France | www.pemphigus.asso.fr | Full member |
| France | Association Pour Aider et Informer Les Syringomyéliques Européens Réunis | www.apaiser.asso.fr | Full member |
| France | Association pour la Lutte contre l'Alcaptonurie | www.alcap.fr | Full member |
| France | Association pour la Lutte contre les maladies Inflammatoires du foie et des voies Biliaires | www.albi-france.org | Full member |
| France | Association pour la Recherche sur la Sclérose Latérale Amyotrophique | www.arsla.org | Associate member |
| France | Association pour l'aide aux personnes concernées par les maladies rares Muckle Wells Syndrome et CINCA | www.amws-cinca.eu | Full member |
| France | Association pour l'information et la prévention de la Drépanocytose | www.apipd.fr | Full Member |
| France | Association pour l'information et la Recherche sur les Maladies Rénales Génétiques | http://www.airg-france.fr | Full member |
| France | Association Sans Diagnostic et Unique | www.asdu.fr | Associate member |
| France | Association Sclérose Tubéreuse De Bourneville | www.astb.asso.fr | Full Member |
| France | Association Sos Desmoïde | www.sos-desmoide.asso.fr | Full Member |
| France | Association Spina Bifida et Handicaps Associés | www.spina-bifida.org | Associate Member |
| France | Association Strümpell-Lorrain | www.asl-hsp-france.org | Full Member |
| France | Association Surrénales | www.surrenales.com | Full Member |
| France | Association Syndrome de Kleine-Levin | kls-france.org | Full member |
| France | Association Syndrome De Moebius France | www.moebius-france.org | Full Member |
| France | Association Syndrome de ROKITANSKY - MRKH | www.asso-mrkh.org | Full Member |
| France | Association Tanguy Moya Moya | www.tanguy-moya-moya.org | Full member |
| France | Association Thera Wanka | http://association-thera-wanka.org | Associate member |
| France | Charcot-Marie-Tooth France | www.cmt-france.org | Full Member |
| France | Cutis Laxa Internationale | www.cutislaxa.org | Full Member |
| France | Debra France | www.debra.fr | Full member |
| France | Dravet Syndrome European Federation | www.dravet.eu | Full member |
| France | Enfants de la Lune Association pour le Xeroderma Pigmentosum | www.enfantsdelalune.org | Full Member |

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| France | European Federation for Hereditary Spastic Paraplegia | www.eurohsp.eu | Full member |
| France | European Federation Lesch-Nyhan Disease | www.LNDE.org | Associate member |
| France | European Federation of Associations of Patients with Haemochromatosis | http://efaph.eu/ | Full member |
| France | Fédération des Malades Drépanocytaires et Thalassémiques SOS Globi | www.sosglobiparis.fr | Full Member |
| France | FITIMA Europe - Fondation International Tierno et Mariam | www.fitima.org | Full member |
| France | FOP France | www.fopfrance.fr | Full member |
| France | France Lymphangiomeiomyomatose (FLAM) | www.francelam.org | Full Member |
| France | France Lymphome Espoir | www.francelymphomeespoir.fr | Full member |
| France | Génération 22 | www.generation22.fr | Full member |
| France | Genespoir: Association Française des Albinismes | www.genespoir.org | Full Member |
| France | GENIRIS | http://associationgeniris.free.fr/ | Full Member |
| France | HTaP France | www.htapfrance.com | Full Member |
| France | Hypophosphatasie Europe | www.hypophosphatasie.com | Full Member |
| France | Incontinentia Pigmenti France | http://incontinentia-pigmenti.fr/ | Full member |
| France | Inflam'œil | www.inflamoeil.org | Full member |
| France | Les Enfants du Jardin | http://www.lesenfantsdujardin.fr/ | Full member |
| France | Les petits bourdons | www.lespetitsbourdons.org | Associate member |
| France | Ligue contre la Cardiomyopathie | http://www.ligue-cardiomyopathie.com/ | Associate Member |
| France | Ligue Nationale Contre Le Cancer | www.ligue-cancer.net | Full member |
| France | Lupus France | www.lupusfrance.com/ | Full Member |
| France | Mosaïques - Association des "X Fragile" | www.xfragile.org | Full member |
| France | Naevus Global | www.naevusglobal.org | Associate member |
| France | Ouvrir Les Yeux - OLY | www.ouvrirlesyeux.org | Full member |
| France | Polyposes Familiales - Aptepf | http://aptepf.free.fr/ | Full Member |
| France | Prader Willi France | www.prader-willi.fr | Full member |
| France | Retina France | www.retina.fr | Full member |
| France | Sanfilippo Sud | http://sanfilipposud.org/ | Full member |
| France | Solidarité Handicap autour des maladies rares | www.solhand-maladiesrares.org | Full member |
| France | Union Huntington Espoir | www.huntington.asso.fr | Full Member |
| France | Union Nationale des Associations Parents et Amis Personnes Handicapées Mentales | www.unapei.org | Associate member |
| France | Union Nationale des Syndromes d'Ehlers-Danlos | www.unsed.org | Full member |
| France | Vaincre la Mucoviscidose | www.vaincrelamuco.org | Full Member |
| France | Vaincre la Papillomatose Respiratoire Récurrente | www.vaincrepr.fr | Full member |
| France | Vaincre les Maladies Lysosomales | www.vml-asso.org | Full Member |

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| France | Valentin - Association des porteurs d'anomalies chromosomiques | www.valentin-apac.org | Full Member |
| France | VHL France | www.vhlfrance.org | Full member |
| France | X Fragile France | www.xfra.org | Full Member |
| France | Xtraordinaire | www.xtraordinaire.org | Full member |
| Georgia | Georgian Foundation for Genetic and Rare Diseases | | Associate member |
| Germany | ACHSE Allianz Chronischer Seltener Erkrankungen e.V. | www.achse-online.de | Full Member |
| Germany | AHC-Deutschland eV | www.ahckids.de | Full member |
| Germany | Aktion Benni & Co e.V. | www.benniundco.de | Full Member |
| Germany | Alpha 1 Netzwerk eV | www.alpha1-netzwerk.de | Full member |
| Germany | ARVC-Selbsthilfe e.V. | www.arvc-selbsthilfe.org | Full member |
| Germany | BSHV für Kinder, Jugendliche und Erwachsene mit seltenen, chronischen Skeletterkrankungen e.V. | bshv-seltene-skelett-erkrankungen.com | Full member |
| Germany | Bundesverband der Clusterkopfschmerzen-Selbsthilfe-Gruppe | www.clusterkopf.de | Full member |
| Germany | Bundesverband für Angeborene Gefäßfehlbildungen e.V. | www.angiodyplasie.de | Full member |
| Germany | Bundesverband Kleinwüchsige Menschen und ihre Familien e.V. | www.bkmf.de | Full Member |
| Germany | Bundesverband Poliomyelitis eV | polio-selbsthilfe.de/willkommen | Full member |
| Germany | Charge Syndrom eV | www.charge-syndrom.de | Full member |
| Germany | Cholesterin & Co eV | http://cholco.org | Associate member |
| Germany | Cystinose Selbsthilfe e.V. | www.leben-eben.com | Full member |
| Germany | Deutsche Ehlers-Danlos Initiative e. V | www.ehlers-danlos-initiative.de | Full member |
| Germany | Deutsche GBS CIDP Initiative e.V | gbs-selbsthilfe.org | Full Member |
| Germany | Deutsche Interessengemeinschaft PKU | www.dig-pku.de | Full member |
| Germany | Deutsche Klinefelter-Syndrom Vereinigung e.V. | www.klinefelter.de | Full member |
| Germany | Deutsche Narkolepsie Gesellschaft e.V. | www.dng-ev.org | Full member |
| Germany | Deutsche Sarkoidose Vereinigung Gemeinnütziger e.V. | www.Sarkoidose.de | Full member |
| Germany | Deutsche Selbsthilfe Angeborene Immundefekte e.V. | www.dsai.de | Full Member |
| Germany | Deutsche Syringomyelie und Chiari Malformation DSCM e.V. | www.deutsche-syringomyelie.de | Full member |
| Germany | DEUTSCHE UVEITIS-ARBEITSGEMEINSCHAFT EV | www.duag.org | Full member |
| Germany | Deutschsprachige Selbsthilfegruppe für Alkaptonurie e.V. | www.dsaku.de | Full member |
| Germany | Ehlers-Danlos Selbsthilfe e. V | www.eds-selbsthilfe-ev.de | Full member |
| Germany | European Association of Patient Organisations of Sarcoidosis (EPOS) | www.sarcoidosis.biz | Full Member |
| Germany | European Congenital Heart Disease Organisation | http://echdo.eu | Associate member |
| Germany | European MEN Alliance | www.Emena.eu | Associate member |
| Germany | European Network for Ichthyosis - eni | http://ichthyosis-eu.freemore.com/ | Full member |

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| Germany | FAUN Stiftung | http://faun-stiftung.de | Associate member |
| Germany | Gaucher Gesellschaft Deutschland e.V. | www.ggd-ev.de | Full Member |
| Germany | Gesellschaft für Mukopolysaccharidosen e.V. | www.mps-ev.de | Full Member |
| Germany | HAE Vereinigung e.V. (Hereditary Angioedema) | www.angiooedem.de | Full Member |
| Germany | Hoffnungsbaum e.V. | www.hoffnungsbaum.de | Full Member |
| Germany | HSP-Selbsthilfegruppe Deutschland e.V. | www.hsp-selbsthilfegruppe.de | Full member |
| Germany | ICA-Deutschland e.V. Förderverein Interstitielle Cystitis | www.ica-ev.de | Full Member |
| Germany | Interessengemeinschaft Epidermolysis Bullosa - Debra Deutschland | www.ieb-debra.de | Full member |
| Germany | Interessengemeinschaft Fragiles-X e.V. | www.frax.de | Full member |
| Germany | Kinder mit Deletionssyndrom 22q11 (KIDS-22Q11) eV | www.kids-22q11.de | Full member |
| Germany | Kinder-Augen-Krebs-Stiftung | www.kinderaugenkrebsstiftung.de | Associate member |
| Germany | Kindernetzwerk e.V | www.kindernetzwerk.de | Full Member |
| Germany | Kindness for Kids Foundation | www.kindness-for-kids.de | Associate Member |
| Germany | Leben mit Behcet - Süddeutschland | | Associate Member |
| Germany | Leben mit Behcet In Deutschland | www.behcet-selbsthilfe.de | Associate Member |
| Germany | Leona e.V. | www.leona-ev.de | Full member |
| Germany | Marfan Europe Network | www.marfan.eu | Full member |
| Germany | Morbus-Osler Selbsthilfe eV | www.morbus-osler.de | Full member |
| Germany | MPN-Netzwerk e.V. | www.Mpn-netzwerk.de | Full member |
| Germany | MPS Europe | mps-europe.org | Full member |
| Germany | Multinational Interstitial Cystitis Association (MICA) | www.mica-online.org | Associate member |
| Germany | Myelitis e.V. | www.myelitis.de | Full member |
| Germany | NCL-Gruppe Deutschland e.V. | www.ncl-deutschland.de | Full Member |
| Germany | Nephie | www.nephie.de | Full member |
| Germany | Netzwerk Hypophysen- und Nebennierenerkrankungen e. V. | www.glandula-online.de | Full member |
| Germany | OIFE - Osteogenesis Imperfecta Federation Europe | www.oife.org | Full Member |
| Germany | Patienten- und Selbsthilfeorganisation für Kinder und Erwachsene mit kranker Speiseröhre | www.keks.org | Full Member |
| Germany | Patientenverband Familiäre Amyloid Polyneuropathie | | Associate member |
| Germany | Peutz-Jeghers-Germany e.V. | peutz-jeghers.eu | Full member |
| Germany | Pro Retina Deutschland e.V. | www.pro-retina.de | Associate Member |
| Germany | Pulmonale Hypertonie e.V. | www.phev.de | Full Member |
| Germany | Sanfilippo Initiative e.V. | www.sanfilippoinitiative.org | Associate member |
| Germany | Selbsthilfe EPP e.V | www.epp-deutschland.de | Full member |
| Germany | Selbsthilfe Ichthyose e.V. | www.ichthyose.de | Full Member |
| Germany | Selbsthilfegruppe Ektodermale Dysplasie e.V. | www.ektodermale-dysplasie.de | Full Member |
| Germany | Selbsthilfegruppe für PXE - Erkrankte Deutschlands e.V. | www.pxe-groenblad.de | Full Member |

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| Germany | Selbsthilfegruppe Glykogenose Deutschland e.V. | www.glykogenose.de | Full member |
| Germany | Selbsthilfeorganisation für Menschen mit Anorektalfehlbildungen | www.soma-ev.de | Full Member |
| Germany | Sklerodermie Selbsthilfe e.V. | www.sklerodermie-selbsthilfe.de | Full member |
| Germany | SMA Europe | www.sma-europe.eu | Full member |
| Germany | Sos-desmoid e.V. | www.sos-desmoid.de | Full member |
| Germany | SSADH-Defizit e.V | ssadh.wordpress.com | Associate member |
| Germany | Stiff-Person Vereinigung Deutschland e.V. | www.stiff-person.de | Full member |
| Germany | The Federation of Esophageal Atresia and Tracheo-Esophageal Fistula Support Groups e.V. | www.we-are-eat.org | Full member |
| Germany | Tom Wahlig Stiftung | www.hsp-info.de | Full member |
| Germany | Verein AHC18+ | https://www.facebook.com/pages/Association-ahc18/606879759444135 | Associate member |
| Germany | Verein VHL (von Hippel - Lindau) betroffener Familien e.V. | www.hippel-lindau.de | Full member |
| Germany | XP – Freu(n)de Mondscheinkinder | www.xeroderm pigmentosum.de | Full member |
| Germany | ZNM - Zusammen Stark! e. V. | www.znm-zusammenstark.org | Associate member |
| Greece | To Mellon Association of people with genetic disorders | www.tomellon.com.gr | Full Member |
| Greece | Association of Greek Friends for Paediatric Immunology Primary Immunodeficiencies "Harmony" | www.paed-anosia.gr | Associate member |
| Greece | Child's Heart | www.kardiapaidiou.gr | Full member |
| Greece | Greek Alliance for Rare Disease | www.pespa.gr | Associate member |
| Greece | Hellenic Cystic Fibrosis Association | www.cysticfibrosis.gr | Full member |
| Greece | Hellenic League against Rheumatism | www.arthritis.org.gr | Associate member |
| Greece | Hellenic Myasthenia Gravis Association | www.myasthenia.gr | Full member |
| Greece | Karkinaki Awareness for Childhood and Adolescent Cancer | www.karkinaki.gr | Associate member |
| Greece | Panhellenic Association of patients & friends with Neurofibromatosis "Life with NF" | | Associate member |
| Greece | Panhellenik Association of Patients with Lysosomal disorders | http://greeklysosomal.gr | Full member |
| Greece | Parents and Friends of People with Rett Synrome Association | www.rettgreece.gr | Associate member |
| Greece | Prader Willi Syndrome Association Hellas | www.pwshellas.gr | Full member |
| Greece | Society of Patients and Friends of Patients with inherited metabolic disease | www.krikoszoiis.gr | Full member |
| Greece | Tuberous Sclerosis Association of Greece | www.pespa.gr | Full Member |
| Greece | VHLFA Alliance in Greece | www.vhl.org | Associate member |
| Guatemala | Asociación Nacional Guatemalteca para las enfermedades de depósito lisosomal | http://angel-lisosomal.org/ | Associate member |
| Guatemala | Procrece | | Associate member |
| Hong Kong, SAR of China | Joshua Hellmann Foundation for Orphan Disease | www.jhforphandisease.org/ | Associate member |

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| Hungary | (Hungarian Haemophilia Society) Magyar Hemofília Egyesület | www.mhe.hu | Full member |
| Hungary | Magyaórszági Mitochondriális Betegek Alapítványa | www.nbia.hu | Full member |
| Hungary | Primer Immunhianyos Betegek Egyesülete | www.pibe.hu | Full member |
| Hungary | Rare Diseases Hungary - RIROSZ | www.rirosz.hu | Full Member |
| Iceland | AHC Federation of Europe | www.ahcfe.eu | Associate member |
| Iceland | Alternating Hemiplegia of Childhood association of Iceland | www.ahc.is | Full member |
| Iceland | Einstok Born - Support Group for Children with Rare Disorders | www.einstokborn.is/ | Full Member |
| Iceland | Gudrun's Rett Syndrome Research Trust | rettenglar.yolasite.com | Associate member |
| Iceland | Hypoparathyroidism Europe (HPTH Europe) | | Associate Member |
| Iceland | The Icelandic Childhood Cancer Parent Organization | www.skb.is | Full Member |
| India | Indian Organization for Rare Diseases | www.I-ORD.org | Associate member |
| India | Organization for Rare Diseases India | www.ordindia.org | Associate member |
| Iran | Rare Disease Foundation of Iran | http://radoir.com | Associate member |
| Ireland | 22q11 Ireland Support Group | www.22q11ireland.org | Full member |
| Ireland | Alpha One Foundation | www.alpha1.ie | Full Member |
| Ireland | Barretstown Serious Fun | www.barretstown.org | Associate member |
| Ireland | Cystic Fibrosis Ireland | www.cfireland.ie | Associate member |
| Ireland | Cystinosis Ireland | cystinosis.ie | Full member |
| Ireland | Fighting Blindness | www.fightingblindness.ie | Full Member |
| Ireland | Friedreich's Ataxia Research Alliance | www.faraireland.ie | Full member |
| Ireland | Huntington's Disease Association of Ireland | www.huntingtons.ie | Full Member |
| Ireland | Irish Cancer Society | www.cancer.ie | Associate member |
| Ireland | Muscular Dystrophy Ireland | www.mdi.ie | Full Member |
| Ireland | Neurofibromatosis Association of Ireland | www.nfaireland.ie | Full Member |
| Ireland | PoPSyCLE Foundation | https://www.facebook.com/Popsycle01/ | Associate member |
| Ireland | Rare Diseases Ireland | http://rdi.ie/ | Full Member |
| Ireland | Sickle Cell and Thalassaemie Ireland | www.sicklecellireland.ie | Full member |
| Ireland | Syringomyelia Ireland | www.syringomyelia.ie | Full Member |
| Ireland | The Cavan Tommy Hoey Trust | http://www.the-cavan-tommy-hoey-trust.org.uk/page1.php | Associate member |
| Ireland | The Irish Fragile X Society | http://fragilexireland.org | Full member |
| Israel | Israel Adult Polyglucosan Body Disease | | Associate member |
| Italy | ABC Associazione Bambini Cri du Chat | www.criduchat.it | Full member |
| Italy | Acondroplasia - Insieme per crescere - Onlus | www.acondroplasiaonlus.com | Full member |
| Italy | AIBWS Onlus | www.aibws.org | Full member |
| Italy | Amici della Porfiria - San Pio da Pietrelcina Onlus | www.porfiria.it | Associate member |
| Italy | Angeli Noonan | www.angelinoonan.it | Full member |

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| Italy | Associazione Persone con Malattie Reumatiche – APMAR Onlus | www.apmar.it | Full member |
| Italy | Associaizione Nazionale Pemfigo/Pemfigoide | www.pemfigo.it | Full member |
| Italy | Associazione Conto Alla Rovescia | www.acar2006.org | Full member |
| Italy | Associazione Famiglie di Soggetti con Deficit Dell'ormone della Crescita ed altre Patologie | www.afadoc.it | Full member |
| Italy | Associazione Italiana Cistite Interstiziale | www.aici-onlus.it | Full Member |
| Italy | Associazione Italiana dei Cardiopatici Congeniti Adulti - Italian GUCH Association | www.aicca.eu | Associate member |
| Italy | Associazione Italiana Estrofia Vescicale-Epispadia Onlus | www.estrofiavescicale.it | Full member |
| Italy | Associazione Italiana Gaucher Onlus - AIG | www.gaucheritalia.org | Full member |
| Italy | Associazione Italiana Glicogenosi | www.aig-aig.it | Full Member |
| Italy | Associazione Italiana Leucodistrofie Unite (AILU) | http://digilander.libero.it/ailu/ | Full member |
| Italy | Associazione Italiana Linfoistocitosi Emofagocitica | www.aileonlus.org | Associate member |
| Italy | Associazione Italiana Malati di Alcaptonuria | www.aimaku.it | Full member |
| Italy | Associazione Italiana malformazione di Arnold-Chiari Child | www.arnold-chiari.it | Full member |
| Italy | Associazione Italiana Miastenia e Malattie Immunodegenerative - Amici del Besta onlus | www.miastenia.it | Full member |
| Italy | Associazione Italiana Miastenia Onlus | www.viverelamiastenia.it | Full Member |
| Italy | Associazione Italiana Mucopolisaccaridosi e Malattie Affini | www.aimps.it | Full Member |
| Italy | Associazione Italiana Niemann Pick e Malattie Affini - Onlus | www.niemannpick.org | Full member |
| Italy | Associazione Italiana per la lotta alle PHTS | www.ptenitalia.org | Full member |
| Italy | Associazione Italiana per le Malformazioni Anorettali | www.aimar.eu | Full member |
| Italy | Associazione Italiana Sclerosi Laterale Amiotrofica (Sez. Lombardia) | http://www.aisla.it | Full Member |
| Italy | Associazione Italiana Sindrome di Poland | www.sindromedipoland.org | Full member |
| Italy | Associazione Italiana Sindrome e Malattia di Behçet (SIMBA) | www.behcet.it | Full member |
| Italy | Associazione Italiana Siringomielia e Arnold Chiari | www.aismac.org | Full member |
| Italy | Associazione Italiana Sostegno Malattie Metaboliche Ereditarie Onlus | www.aismme.org | Full Member |
| Italy | Associazione Italiana Teleangectasia Emorragica Italiana - HHT ONLUS | www.hhtonlus.com | Full member |
| Italy | Associazione LAM Italia Onlus | www.lam-italia.org | Full member |
| Italy | Associazione Ligure Thalassemicci Onlus | www.althonlus.org | Full member |
| Italy | Associazione Malati di Hailey Hailey Disease | www.amahhd.it | Full member |
| Italy | Associazione Malattie Rare Dell'Alta Murgia Onlus | www.amaram.it | Associate member |
| Italy | ASSOCIAZIONE PER LE IMMUNODEFICIENZE PRIMITIVE ONLUS | www.aip-it.org | Full member |

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| Italy | Associazione per l'informazione e lo studio della Accondroplasia | www.aisac.it | Full Member |
| Italy | Associazione Persone Williams Italia Onlus | www.apwitalia.org | Associate member |
| Italy | Associazione Sclerosi Tuberosa | www.sclerosituberosa.org | Full Member |
| Italy | Associazione Sindrome Nefrosica Italia | www.asnit.org | Full member |
| Italy | Associazione Studio Malattie Metaboliche Ereditarie Onlus | www.cometaasmme.org | Full Member |
| Italy | Associazione Veneta per la Lotta alla Talassemia | www.avlt.it | Full Member |
| Italy | CIDP Italia Onlus | www.cidp.it | Full member |
| Italy | Collagene VI Italia Onlus - COL6 | www.col6.it | Full member |
| Italy | costello.cfc - associazione italiana sindrome di costello - cardiofaciocutanea - rasopatie - onlus | www.sindromedicostello.it | Full member |
| Italy | DEBRA Italia ONLUS – Associazione per la Ricerca sull'Epidermolisi Bollosa | www.debraitaliaonlus.org | Full Member |
| Italy | Dravet Italia Onlus | www.dravet-italia.org | Full member |
| Italy | Federazione Sindrome di Prader Willi Italia | www.praderwilli.it | Full Member |
| Italy | FOP Italia Onlus | www.fopitalia.it | Full member |
| Italy | Gli amici di Daniela | www.amicidaniela.it | Associate member |
| Italy | Gruppo "Italia - Glioblastoma Multiforme - cancro al cervello" | | Associate member |
| Italy | Gruppo Italiano per la Lotta alla Sclerodermia ONLUS | www.sclerodermia.net | Full member |
| Italy | HHT Europe | www.hhteurope.org | Full member |
| Italy | Incontinentia Pigmenti Associazione Italiana Onlus | www.incontinentiapigmenti.it | Associate member |
| Italy | La strada per l'Arcobaleno | www.stradaperlarcobaleno.com | Full member |
| Italy | Lega Italiana Sclerosi Sistemica Onlus | www.sclerosistemica.info | Full member |
| Italy | Lega per la Neurofibromatosi 2-Onlus | www.neurofibromatosi2.it | Full member |
| Italy | LND Famiglie Italiane Onlus | www.lnd-it.com | Full member |
| Italy | p63 EEC Syndrome International net work word communication - MALATTIE RARE ONLUS | www.sindrome-eec.it | Associate member |
| Italy | Pandas Italia | www.pandasitalia.com | Full member |
| Italy | Parent Project Onlus | www.parentproject.it | Full Member |
| Italy | PKS Kids Italia Onlus | www.pksitalia.org | Full member |
| Italy | Retina Italia onlus | http://www.retinaitalia.org/ | Full member |
| Italy | Ring 14 International | www.ring14.org | Full member |
| Italy | SOD Italia - Associazione Italiana Displasia Setto Ottica e Ipoplasia del Nervo Ottico | www.soditalia.it | Full member |
| Italy | UNIAMO - Rare Diseases Italy | www.uniamo.org | Full Member |
| Italy | Unione Italiana Ittiosi | http://www.ittiosi.it | Full member |
| Italy | United Onlus | www.unitedonlus.org | Full member |
| Italy | Visus - Associazione tra affetti aa Retinite Pigmentosa | | Full Member |
| Italy | World Federation of Incontinence Patients | www.wfip.org | Associate member |

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| Italy | XLPRD International Association | www.xlprd.com | Associate member |
| Japan | Japan Patient Association | www.nanbyo.jp | Associate member |
| Kazakhstan | Patients with cancer and rare diseases support association | | Associate member |
| Latvia | Association of people with special needs "Motus Vita" | http://www.motusvita.lv/index.php?lang=en | Associate member |
| Latvia | Empty Nose Syndrome International Association | ensassociation.org | Associate member |
| Latvia | Latvian Alliance for Rare Diseases | www.retasslimibas.lv | Associate member |
| Latvia | Rare Disease Association "Caladrius" | | Associate member |
| Lebanon | Lebanese association for neuromuscular diseases | landforhope.org | Associate member |
| Lithuania | Association for Children Rare Diseases | www.retosligos.lt | Associate member |
| Lithuania | Community of Oncohematological Patient Organisations KRAUJAS | www.kraujas.lt | Full member |
| Luxembourg | ALAN - Maladies Rares Luxembourg | www.alan.lu | Full Member |
| Luxembourg | den i asbl Syndrome de Marfan | www.den-i.lu/ | Associate member |
| Luxembourg | Een Häerz Fir Kriibskrank Kanner Asbl | www.kriibskrankkanner.lu | Full member |
| Luxembourg | Fondatioun Kriibskrank Kanner | www.fondatioun.lu | Associate member |
| Luxembourg | Rett Syndrome Europe | www.rettsyndrome.eu | Full member |
| Malaysia | Malaysia Metabolic Society | www.mms.my | Associate member |
| Malaysia | Malaysian Rare Disorders Society | www.mrds.org.my | Associate member |
| Malta | National Alliance for Rare Diseases Support - Malta | www.rarediseasesmalta.com | Associate member |
| Mexico | Proyecto Pide un Deseo Mexico iap | www.pideundeseo.org | Associate member |
| Mexico | Red Sanfilippo | www.redsanfilippo.org | Associate member |
| Moldova | Copiii ploii | https://www.facebook.com/AO-Copiii-Ploii-686485228086936/ | Full member |
| Montenegro | National Organisation for Rare Diseases | www.rijetkebolesti.com | Associate member |
| Morocco | Association Marocaine de la Fièvre Méditerranéenne Familiale et des autres fièvres récurrentes | | Associate member |
| Morocco | Sun'Hop | | Associate member |
| Nepal | GBS/CIDP Foundation Nepal | www.gbs-cidp-nepal.org/ | Associate member |
| Netherlands | ALS Patients Connected | www.alspatientsconnected.com | Full member |
| Netherlands | Autosomaal Dominant Cerebellaire Ataxie-Vereniging Nederland | www.ataxie.nl | Full Member |
| Netherlands | Bijniervereniging NVACP | www.nvacp.nl | Full Member |
| Netherlands | Childhood Cancer International | www.childhoodcancerinternational.org | Full member |
| Netherlands | CMTC-OVM | www.cmtc.nl | Full Member |
| Netherlands | Cornelia de Lange Syndrome World Federation | www.cdlsworld.org | Full member |
| Netherlands | European Society for Phenylketonuria | www.espku.org | Associate member |
| Netherlands | European VHL (von Hippel-Lindau) Federation | www.vhl-europa.org | Associate member |
| Netherlands | European Waldenström Macroglobulinemia Network | www.waldenstrom.eu | Full member |

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| Netherlands | Fabry Support & Informatie Groep Nederland | www.fabry.nl | Full member |
| Netherlands | Fibrodysplasia Ossificans Progressiva Stichting Nederland | www.fopstichting.nl | Full member |
| Netherlands | FSHD Europe | http://fshd-europe.info | Full member |
| Netherlands | International Mito Patients | www.mitopatients.org | Full member |
| Netherlands | International Painful Bladder Foundation | www.painful-bladder.org | Associate Member |
| Netherlands | International Porphyria Patient Network | www.ippn.info | Associate member |
| Netherlands | Interstiële cystitis Patientenvereniging | www.icpatienten.nl | Full member |
| Netherlands | ITP Patientenvereniging | www.itp-pv.nl | Full member |
| Netherlands | KAISZ Children with a autoimmune or autoinflammatory disease | www.kaisz.nl | Full member |
| Netherlands | MSS (Marshall-Smith Syndrome) Research Foundation | www.marshallsmith.org | Full member |
| Netherlands | Nederlands Netwerk voor Lymfoedeem en Lipoedeem | www.lymfoedeem.nl | Associate member |
| Netherlands | Nederlandse Hypofyse Stichting (Dutch Pituitary Foundation) | www.hypofyse.nl | Full member |
| Netherlands | Nederlandse Phenylketonurie Vereniging / Dutch PKU Association | Www.pkuvereniging.nl | Full member |
| Netherlands | NephcEurope | http://nephceurope.eu/nc/ | Associate member |
| Netherlands | Netherlands Liver Patients Association | www.leverpatientenvereniging.nl | Full member |
| Netherlands | Neurofibromatose Vereniging Nederland | www.neurofibromatose.nl | Full member |
| Netherlands | OSCAR Nederland | www.oscarnederland.nl | Full member |
| Netherlands | Patientenorganisatie Fibreuze Dysplasie | http://www.fibreuzedysplasie.eu | Full member |
| Netherlands | PSC Patients Europe | http://pscpatientseurope.org | Full member |
| Netherlands | Sarcoidose.nl | www.sarcoidose.nl | Full member |
| Netherlands | Stichting AA & PNH contactgroep | http://www.aaenpnh.nl | Full member |
| Netherlands | Stichting Amyloidose Nederland SAN | amyloidose.nl | Full member |
| Netherlands | Stichting Christianson Syndrome Europe | https://cs-europe.org/nl/ | Associate member |
| Netherlands | Stichting Hart4Onderzoek / Heart4Research | http://www.hart4onderzoek.nl/over- een.html | Associate member |
| Netherlands | Stichting Histiocytose Nederland | www.histio.nl | Full Member |
| Netherlands | Stichting Ijzersterk | www.stichtingijzersterk.nl | Associate member |
| Netherlands | Stichting NET-groep | www.net-kanker.nl | Full member |
| Netherlands | Stichting Shwachman Diamond Syndrome Support Holland | www.shwachman.nl | Full member |
| Netherlands | Stichting Stofwisselkracht | www.stofwisselkracht.nl | Full member |
| Netherlands | Stichting Terre - Rett Syndrome Foundation | www.stichtingterre.nl | Full member |
| Netherlands | STICHTING VOOR AFWEERSTOORNISSEN | www.stichtingvoorafweerstoornissen.nl | Full Member |
| Netherlands | Stichting Zeldzame Bloedziekten | www.bloedziekten.nl | Associate member |
| Netherlands | Thyroid Cancer Alliance | www.thyroidcanceralliance.org | Full member |
| Netherlands | United Parent Projects Muscular Dystrophy | www.uppm.org | Full member |
| Netherlands | Vasculitis Stichting | www.vasculitis.nl | Full member |
| Netherlands | Vereniging Spierziekten Nederland - Dutch Association For Neuromuscular Disease | www.vsn.nl | Full member |

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| Netherlands | Volwassenen, Kinderen en Stofwisselingsziekten | www.stofwisselingsziekten.nl | Full Member |
| Netherlands | VSOP - Vereniging Samenwerkende Ouder En Patiëntenorganisaties | www.vsop.nl | Full Member |
| Netherlands | World Alliance of Pituitary Organizations | www.wapo.org | Associate member |
| New Zealand | New Zealand Organisation for Rare Disorders | www.nzord.org.nz | Associate Member |
| Norway | Aniridi Norge | www.aniridi.no | Full member |
| Norway | Aniridia Europe | www.aniridia.eu | Full member |
| Norway | European Huntington Association | http://eurohuntington.org/ | Full member |
| Norway | FRAMBU - Resource Centre for Rare Disorders | www.frambu.no | Full member |
| Norway | Morbus Addison Association Norway | www.addison.no | Full member |
| Norway | MPS-foreningen i Norge | http://mpsforeningen.no | Associate member |
| Norway | Nordic hypoPARA Organisation | www.hypopara-nordic.org | Full Member |
| Norway | Norsk forening for Arvelig Spastisk Paraparese / Ataksi | www.naspa.no | Full member |
| Norway | NORSK FORENING FOR EHLERS-DANLOS SYNDROM | www.eds-foreningen.no | Full Member |
| Norway | Norsk Forening for Osteogenesis Imperfecta | www.nfoi.no | Full member |
| Norway | Norsk Forening for Tuberos Sklerose | www.nfts.no | Full member |
| Norway | Oslerforeningen Norge | www.osler.no | Full member |
| Poland | Debra Polska | www.debra-kd.pl | Full member |
| Poland | Fundacja Sanfilippo | www:sanfilippo.org.pl | Associate member |
| Poland | Fundacja SMA (SMA Foundation Poland) | www.fsma.pl | Full member |
| Poland | Fundacja Umiec Pomagac (Foundation for RD MPS) | www.umiecpomagac.org | Full member |
| Poland | MATIO-Fundacji Pomocy Rodzinom i Chorym na Mukowiscydoz? | www.mukowiscydoza.pl | Full Member |
| Poland | Polish National Forum on the Treatment of Orphan Diseases - ORPHAN | www.rzadkiechoroby.pl | Full member |
| Poland | Polish PKU and RD Association "Ars Vivendi" | www.fenyloketonuria.org | Full member |
| Poland | Polish Society of MPS and Related Diseases | www.mps-society.pl | Full member |
| Poland | Polskie Stowarzyszenie na Rzecz Osób z AHC | | Associate member |
| Poland | Rett Syndrome Poland - Ogólnopolskie Stowarzyszenie Pomocy Osobom z Zespo?em Retta | www.rettsyndrome.pl | Full member |
| Poland | The Dina Radziwillowa Child's Heart Foundation | www.sercedziecka.org.pl | Full member |
| Portugal | Aliança Portuguesa de Associações das Doenças Raras | http://aliancadoencasraras.org/ | Associate member |
| Portugal | APLL - Associação Portuguesa de Leucemias e Linfomas | www.apll.org | Full member |
| Portugal | Associação Nacional de Displasias Ósseas | www.andoportugal.org | Associate member |
| Portugal | Associação Portuguesa CDG e outras Doenças Metabólicas | www.apcdg.com | Associate member |
| Portugal | Associação Portuguesa de Charcot-Marie-Tooth | apcmt.org.pt | Full member |

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| Portugal | ASSOCIAÇÃO PORTUGUESA DE DOENTES NEUROMUSCULARES | www.apn.pt | Full Member |
| Portugal | Associação Portuguesa de Osteogénese Imperfeita | www.apoi.pt | Full member |
| Portugal | Associação Sanfilippo Portugal | www.sanfilippoportugal.com | Full member |
| Portugal | FEDRA - Federação Portuguesa de Doenças Raras (suspended) | www.fedra.pt | Associate member |
| Portugal | Rarissimas - Associação Nacional de Deficiências Mentais e Raras | www.rarissimas.pt | Associate member |
| Romania | Asociația Copilul Meu-Inima Mea | www.acmim.ro | Full member |
| Romania | Asociația Persoanelor Cu Talasemie Majora | www.talasemia.ro | Full member |
| Romania | Asociația Română? de Cancere Rar | www.arcrareromania.ro | Associate member |
| Romania | Asociația Romana Spina Bifida si Hidrocefalie | https://www.facebook.com/ARSBH/ | Associate member |
| Romania | Asociația SMACARE | www.amiotrofie-spinala.ro | Full member |
| Romania | Asociația Werdnig Hoffman AWH | www.werdnighoffman.ro | Full member |
| Romania | Asociația Williams Syndrome | www.williams-syndrome.ro | Full Member |
| Romania | Autoimmune Diseases Patients Association | www.apaa.ro | Associate member |
| Romania | Mastocytosis Support Association Romania | www.mastocitoza.ro | Associate member |
| Romania | Romanian Myasthenia Gravis Association | www.miastenie.ro | Full member |
| Romania | Romanian National Alliance for Rare Diseases | bolirareromania.ro | Full member |
| Romania | Romanian Prader Willi Association | www.apwromania.ro | Full Member |
| Russian Federation | Fabry Russia | www.fabryrufa.ru | Associate member |
| Russian Federation | Help to Cystic Fibrosis Patients | | Full member |
| Russian Federation | Interregional public organisation for Gaucher disease | www.gaucher.ru | Full member |
| Russian Federation | Interregional Public Organisation of patients with Fabry Disease "The Road to Life" | www.fabryufa.ru | Full member |
| Russian Federation | MPS Russia | www.mps-russia.org | Full member |
| Russian Federation | National Association of Patients with Rare Diseases "GENETICA" | www.nacgenetic.ru | Associate member |
| Russian Federation | NGO "Fragile children" | www.osteogenez.ru | Full member |
| Russian Federation | Russian association of rare diseases | www.rare-diseases.ru | Full member |
| Russian Federation | Russian Interregional public organization "Inter-regional support centre for patients with Aniridia " Iris" | www.aniridia.ru | Associate member |
| Russian Federation | Russian Patient Union | http://www.patients.ru/en | Associate member |
| Russian Federation | Russian Rett Syndrome Association | www.rett syndrome.ru | Associate member |
| Russian Federation | SPIPORZ Union of patients with rare diseases and rare disease patients organisations | www.spiporz.ru | Associate member |
| Russian Federation | The Association of primary immunodeficiency patients | www.oppid.ru | Full member |
| Serbia | Child rare disease support and research association Life | www.zivotorg.org | Associate member |

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| Serbia | Childhood Cancer Parent Organisation "Zvoncica" | www.zvoncica.org | Full member |
| Serbia | Lymphoma Patients' Association | www.lipa.org.rs | Associate member |
| Serbia | National Organization for Rare Diseases, Serbia | www.norbs.rs | Full member |
| Singapore | Rare Disorders Society (Singapore) | www.rdss.org.sg | Associate member |
| Slovakia | Debra SR | www.debra-slovakia.org | Full member |
| Slovakia | Organisation of Muscular Dystrophy in the Slovak Republic | www.omdvsr.sk | Full member |
| Slovakia | Slovak Alliance of Rare Diseases | www.sazch.sk | Associate member |
| Slovakia | Slovak Cystic Fibrosis Association | www.cfasociacia.sk | Full member |
| Slovakia | Zdruzenie Ojedlinelych Genetickyoch Ochorenie | http://www.zogo.sk/ | Associate member |
| Slovenia | Association of patients with blood diseases - Drustvo Bolnikov S Krvnimi Boleznimi | www.drustvo-bkb.si | Full member |
| Slovenia | Debra Slovenia - Drustvo DEBRA Slovenija | www.debra-slovenia.si | Full member |
| Slovenia | EAMDA - European Alliance of Neuromuscular Disorders Associations | www.eamda.eu | Full Member |
| Slovenia | Fabry Patients Association Slovenia / Društvo bolnikov s Fabryjevo boleznijo Slovenije | | Full member |
| Slovenia | Foundation of Child Neurology | http://peuetro.peukr.si/english/foundation/ | Associate Member |
| South Africa | Primary Immunodeficiency Network of South Africa | www.pinsa.org.za | Associate member |
| South Africa | Rare Disease Society of South Africa | www.rarediseases.co.za | Associate member |
| Spain | Acción y Cura para Tay-Sachs - ACTAYS | www.actays.org | Full member |
| Spain | Alianza Española de Familias de Von Hippel Lindau | www.alianzavhl.org | Full Member |
| Spain | Asociació Catalana de las Neurofibromatosis | http://www.acnefi.com/castella/gamhome.htm | Full Member |
| Spain | Asociación Andaluza contra la Fibrosis Quística | www.fibrosisquistica.org/andaluza/ | Full Member |
| Spain | Asociación Andaluza de Pacientes con Síndrome de Tourette y Trastornos Asociados | www.tourette.es | Full Member |
| Spain | Asociación Artrogriposis Múltiple Congénita | www.amc-esp.blogspot.com | Full member |
| Spain | Asociacion Chiari y Siringomielia del Principado de Asturias | www.chyspa.org | Full member |
| Spain | Asociación de Afectados de Neurofibromatosis | www.neurofibromatosis.es | Full member |
| Spain | Asociación de Afectados por Displasia Ectodérmica | www.displasiaectodermica.org | Full member |
| Spain | Asociación de Afectados por Hiperinsulinismo Congénito | www.afhico.org | Full member |
| Spain | Asociacion de Atrofia de Nervio Optico de Leber | www.asanol.com | Full member |
| Spain | Asociación de Epidermolisis Bullosa de España (DEBRA España) | www.debra.es | Full member |
| Spain | Asociación de Esclerodermia Castellon | www.esclerodermia-adec.org | Full Member |
| Spain | Asociacion de Familiares y afectados por Lipodistrofias | www.aelip.org | Full member |
| Spain | Asociacion de Familiares y Enfermos de FPI y FPF | www.afefpi.org | Full member |

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| Spain | Asociación de Hemoglobinuria Paroxística Nocturna | www.hpne.org | Associate member |
| Spain | Asociación de Huesos de Cristal de España | www.ahuce.org | Full Member |
| Spain | Asociación de las Mucopolisacaridosis y Síndromes Relacionados | www.mpse.org/ | Full Member |
| Spain | Asociación de Nevus Gigante Congénito | http://asonevus.org/ | Full Member |
| Spain | Asociación española del síndrome CDG, defectos congénitos de la glicosilación | http://webs.ono.com/aescdg | Associate member |
| Spain | Asociación Española Aniridia | www.aniridia.es | Full Member |
| Spain | Asociación Española de Afectados por Sarcoma | www.aesarcomas.org | Full member |
| Spain | Asociación Española De Angioedema Familiar | www.angioedema-aedaf.org | Full Member |
| Spain | Asociación Española de Enfermos de Glucogenosis | www.glucogenosis.org | Full Member |
| Spain | Asociación Española de Enfermos de Pompe | www.asociaciondepompe.org | Associate member |
| Spain | Asociación Española de Enfermos y Familiares de la Enfermedad de Gaucher España | www.aefegaucher.es | Full Member |
| Spain | Asociación Española de Esclerodermia | www.esclerodermia.com | Full Member |
| Spain | Asociación Española de Familiares y Enfermos de Wilson | www.enfermadedewilson.org | Full Member |
| Spain | Asociación Española de Fibrodisplasia Osificante Progresiva | www.aefop-es.org | Full member |
| Spain | Asociación Española de Fiebre Mediterránea Familiar | http://fmf.org.es | Full member |
| Spain | Asociación Española de Ictiosis | www.ictiosis.org | Full member |
| Spain | Asociación Española de Mastocitosis y Enfermedades Relacionadas | www.mastocitosis.com | Full member |
| Spain | Asociación Española de Paraparesia Espástica Familiar Strümpell-Lorrain | www.aepf.org | Full member |
| Spain | Asociación Española de Porfiria | www.porfiria.org | Full Member |
| Spain | Asociación Española de Raquitismos y Osteomalacia Heredados | webaerho.wixsite.com/aerhyo | Associate member |
| Spain | Asociación Española de Síndrome De Poland | www.aesip.es | Full member |
| Spain | Asociación Española del Síndrome de Joubert | http://webs.ono.com/sindrome_joubert/ | Full Member |
| Spain | Asociación Española Síndrome de Sjögren | www.aesjogren.org | Full Member |
| Spain | Asociación HHT España | www.asociacionhht.org | Full Member |
| Spain | Asociación Miradas que Hablan Duplicación Mecp2 | www.duplicacionmecp2.es | Full member |
| Spain | Asociación Nacional Amigos de Arnold Chiari | www.chiari.biz | Full member |
| Spain | Asociación Nacional de Hipertensión Pulmonar | www.hipertensionpulmonar.es | Full member |
| Spain | Asociación Nacional Síndrome de Apert y otras Craneosinostosis Síndromicas | www.ansapert.org | Full Member |
| Spain | Asociación Síndrome de Angelman | www.angelman-asa.org | Full Member |
| Spain | Asociación Síndrome de Lowe de España | www.sindromelowe.es | Full member |

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| Spain | Asociación Síndrome Lesch Nyhan España | www.asociacionlesch-nyhan.org.es | Full member |
| Spain | Asociacion Stop Sanfilippo | www.stopsanfilippo.org | Associate member |
| Spain | Asociación Xeroderma Pigmentosum | https://xerodermapigmentosum.es/ | Full member |
| Spain | Associacio Catalana de la Deleccio 22Q | www.22q.cat | Full member |
| Spain | Associació Catalana de Síndrome de Sjögren | | Full member |
| Spain | Associació d'Apràxia Ocular i Malalties Associades | apraxiaocular.blogspot.com | Associate member |
| Spain | Asociación Catalana de Enfermedades Neuromusculares | www.asemcatalunya.com | Full member |
| Spain | De Neu - Asociación de Enfermedades de los Neurotransmisores | www.deneu.org | Full member |
| Spain | D'Genes Asociación de Enfermedades Raras de Murcia | http://www.dgenes.es/ | Full member |
| Spain | Dravet Syndrome Foundation, Delegacion en Espana | www.dravetfoundation.eu | Associate member |
| Spain | Duchenne Parent Project España | www.duchenne-spain.org | Full member |
| Spain | European Network for Rare and Congenital Anaemias | www.enerca.org | Associate Member |
| Spain | FEDER - Federación Española de Enfermedades Raras | www.enfermedades-raras.org | Full Member |
| Spain | Federació Catalana de Malalties Minoritàries | www.fcmpf.entitatsbcn.net | Full member |
| Spain | Federación de Asociaciones de Retinosis Pigmentaria de España | www.retinosisfarpe.org | Full member |
| Spain | Federación de Ataxias de España | www.fedaes.org | Full Member |
| Spain | Federación Española de Enfermedades Neuromusculares | www.asem-esp.org | Full Member |
| Spain | Federación Española de Fibrosis Quística | http://www.fibrosis.org/ | Full Member |
| Spain | Federación Española de Hemofilia | www.hemofilia.com | Full Member |
| Spain | Federación Española de Malformación de Chiari y patologías asociadas | www.femacpa.com | Associate member |
| Spain | Federacion Espanola de Padres con Ninos con Cancer | www.cancerinfantil.org | Full member |
| Spain | Federación Española del Síndrome X Frágil | www.xfragil.org | Full member |
| Spain | Fundación Andrés Marcio, niños contra la laminopatía | www.fundacionandresmarcio.org | Full member |
| Spain | Fundacion Menudos Corazones | www.menudoscorazones.org | Full member |
| Spain | Fundación Niemann-Pick de España | www.fnp.es | Full member |
| Spain | Fundación Síndrome 5p menos | www.fundacionsindrome5p.org | Full member |
| Spain | Fundación Síndrome de Moebius | www.moebius.org | Full Member |
| Spain | Fundacion Síndrome de West | www.sindromedewest.org | Full member |
| Spain | Fundación Síndrome Wolf Hirschhorn 4p- | www.4pmenos.org | Full member |
| Spain | hipertension pulmonar españa organizacion de pacientes - Hpe-org | www.hipertension-pulmonar.com | Associate member |
| Spain | Instituto de Investigación y Desarrollo social de Enfermedades poco Frecuentes | www.pocofrecuentes.org | Associate member |
| Spain | Miquel Valls Foundation (Fundacion Privada Catalana de Esclerosi Lateral Amiotrofica) | www.elacat.org | Associate member |

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| Sweden | Agrenska | www.agrenska.se | Full Member |
| Sweden | Aorta Dissektion Föreningen Skandinavien | www.aortadissektion.com | Full member |
| Sweden | European Dysmelia Reference Information Centre | www.edric.eu | Full member |
| Sweden | Neuroförbundet / Swedish Association of persons with Neurological disabilities | http://neuroforbundet.se | Associate member |
| Sweden | Prader Willi Syndrome Association in Sweden | www.prader-willi.se | Full member |
| Sweden | Primär immunbrist organisationen | www.pio.nu | Full member |
| Sweden | Rare Diseases Sweden (Riksförbundet Sällsynta Diagnoser) | www.sallsyntadiagnoser.se | Full Member |
| Sweden | Svensk förening för Hypoparatyreodism | www.hypopara-nordic.org | Associate member |
| Sweden | Svenska Marfanföreningen | www.marfanforeningen.se/ | Full Member |
| Sweden | Swedish Cystic Fibrosis Association | www.rfcf.se | Full Member |
| Sweden | Swedish EDS Association (EDS Riksförbund) | www.ehlers-danlos.se | Full Member |
| Sweden | Swedish MPS Society | www.mpsforeningen.se | Full member |
| Sweden | Thyroid Federation International | www.thyroid-fed.org | Associate member |
| Sweden | Wilhelm Foundation | www.wilhelmfoundation.org | Full member |
| Switzerland | Association enfance et Maladies Orphelines | www.aemo.ch | Associate member |
| Switzerland | Association Suisse Romande Intervenant contre les Maladies neuro-Musculaires | www.asrimm.ch | Full Member |
| Switzerland | Blackswan Foundation | www.blackswanfoundation.ch | Associate member |
| Switzerland | Esperare | www.esperare.org | Associate member |
| Switzerland | FMF & AID Global Association | www.fmfandaid.org | Associate member |
| Switzerland | Fondation Sanfilippo Suisse | www.fondation-sanfilippo.org | Associate member |
| Switzerland | Foundation Orphanhealthcare | www.orphanhealthcare.com | Associate member |
| Switzerland | FRAXAS - Association X Fragile Suisse | www.fraxas.ch | Full Member |
| Switzerland | HAEi - Hereditary Angioedema International Association | http://www.haei.org | Associate member |
| Switzerland | HHT-Swiss | www.hhtswiss.org | Associate member |
| Switzerland | Leukemia Patient Advocates Foundation | www.cmladvocates.net | Associate member |
| Switzerland | MaRaVal - maladies rares valais - seltene krankheiten wallis | http://www.maraval.ch/ | Associate member |
| Switzerland | Marfan Foundation Switzerland (Marfan Stiftung Schweiz) | www.marfan.ch | Full Member |
| Switzerland | Prader Willi Syndrom Vereinigung Schweiz | www.prader-willi.ch | Full Member |
| Switzerland | ProRaris | www.prorarais.ch | Full member |
| Switzerland | Retina International | www.retina-international.org | Full member |
| Switzerland | Schweizerische Gesellschaft für Familiäre Formen der Hypercholesterinämie | www.sgfh.ch | Associate member |
| Switzerland | Schweizerische Gesellschaft für Porphyrie | www.porphyrria.ch | Full member |
| Switzerland | Selbsthilfe Ichthyose Schweiz | www.ichthyose.ch | Associate member |
| Switzerland | SMA Schweiz | www.sma-schweiz.ch | Associate member |
| Taiwan, Province Of China | Taiwan Foundation for Rare Disorders | www.tfrd.org.tw | Associate Member |

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| The Former Yugoslav Republic of Macedonia | Association for help and support of patients and their caregivers with haematological diseases | www.hema.org.mk | Associate member |
| The Former Yugoslav Republic of Macedonia | Association for persons with Spinal Muscular Atrophy- STOP SMA | https://www.facebook.com/STOP-SMA-Macedonia-%D0%A1%D0%A2%D0%9E%D0%9F-%D0%A1%D0%9C%D0%90-1916753535041997/ | Associate member |
| The Former Yugoslav Republic of Macedonia | Life with Challenges | http://challenges.mk/?p=2288&lang=en | Full member |
| The Former Yugoslav Republic of Macedonia | National Alliance for Rare Diseases of R. Macedonia | | Full member |
| The Former Yugoslav Republic of Macedonia | Save Liver Association of Patients with liver diseases | facebook/SLAPSaveLiverAssociationforPatients | Full member |
| The Former Yugoslav Republic of Macedonia | Zdruzenie za Cisticna Fibroza (Macedonian CF Association) | www.cf.mk | Full member |
| Turkey | KifDER | www.kifder.org.tr | Associate member |
| Turkey | Mukopolisakkaridoz ve Benzeri Lizozomal Depo Hastaliklari Dernegi | www.mpsturk.org | Associate member |
| Turkey | Yuzumle Mutluyum Dernegi | www.yuzumlemutluyum.org.tr | Associate member |
| Ukraine | Association of patients with pulmonaty hypertension | www.pha.org.ua | Full member |
| Ukraine | Charitable Foundation of Sister Dalila | http://poryatunok.info/uk/ | Associate member |
| Ukraine | Kharkiv's Charitable Foundation - "Children with Spinal Muscular Atrophy" | www.csma.org.ua | Full Member |
| Ukraine | Non-governmental Organization "Rare Diseases of Ukraine" | http://rarediseases.org.ua/index.php/en/ | Associate member |
| Ukraine | Ukrainian Association Crystal People | http://ostimperfecta.wix.com/oiua | Associate member |
| Ukraine | Ukrainian National charitable fund ZAPORUKA | www.zaporuka.com.ua | Associate member |
| Ukraine | Ukrainian Union of Patients' Organisations | www.patient.in.ua | Associate member |
| Ukraine | Ukranian Parent Project "Mio-Life" | miolife.org | Associate member |
| Ukraine | UPO-Ukrainian association of help for patients with CF | facebook.com/cysticfibrosisua | Full member |
| United Kingdom of Great Britain and Northern Ireland | Advocacy for Neuroacanthocytosis Patients | www.naadvocacy.org | Associate member |
| United Kingdom of Great Britain and Northern Ireland | AKU Society | http://www.aksociety.org | Full member |
| United Kingdom of Great Britain and Northern Ireland | ALD LIFE | www.aldlife.org | Associate member |
| United Kingdom of Great Britain and Northern Ireland | Alstrom Syndrome Europe | | Associate member |

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| United Kingdom of Great Britain and Northern Ireland | Alstrom Syndrome UK | www.alstrom.org.uk | Full Member |
| United Kingdom of Great Britain and Northern Ireland | Amyloidosis Research Consortium UK | | Associate member |
| United Kingdom of Great Britain and Northern Ireland | Ann Edgar Charitable Trust - Neuroendocrine Tumour Support | www.taect.scot | Full member |
| United Kingdom of Great Britain and Northern Ireland | Annabelle's Challenge | www.annabelleschallenge.org | Full member |
| United Kingdom of Great Britain and Northern Ireland | Association for Glycogen Storage Disease | www.agsd.org.uk | Full member |
| United Kingdom of Great Britain and Northern Ireland | Association for Multiple Endocrine Neoplasia Disorders | www.amend.org.uk | Full member |
| United Kingdom of Great Britain and Northern Ireland | Ataxia UK | www.ataxia.org.uk | Full member |
| United Kingdom of Great Britain and Northern Ireland | Batten Disease Family Association | http://www.bdfa-uk.org.uk/about-batten-disease | Full member |
| United Kingdom of Great Britain and Northern Ireland | Behcet's UK | www.behcets.org.uk | Full member |
| United Kingdom of Great Britain and Northern Ireland | Brittle Bone Society | www.brittlebone.org | Associate member |
| United Kingdom of Great Britain and Northern Ireland | Cambridge Rare Disease Network (CRDN) | www.camraredisease.com | Associate member |
| United Kingdom of Great Britain and Northern Ireland | Cancer 52 | www.cancer52.org.uk | Associate member |
| United Kingdom of Great Britain and Northern Ireland | Cavernoma Alliance UK | www.cavernoma.org.uk | Full member |
| United Kingdom of Great Britain and Northern Ireland | Child Growth Foundation | www.childgrowthfoundation.org | Full member |
| United Kingdom of Great Britain and Northern Ireland | ChILD Lung Foundation | www.childlungfoundation.org | Associate member |
| United Kingdom of Great Britain and Northern Ireland | Children's Liver Disease Foundation | www.childliverdisease.org | Associate member |
| United Kingdom of Great Britain and Northern Ireland | Ciliopathy Alliance | www.ciliopathyalliance.org | Full member |
| United Kingdom of Great Britain and Northern Ireland | Contact a Family | www.cafamily.org.uk | Full Member |

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| United Kingdom of Great Britain and Northern Ireland | Cystinosis Foundation of the UK | www.cystinosis.org.uk | Full member |
| United Kingdom of Great Britain and Northern Ireland | Dancing Eye Syndrome Support Trust | www.dancingeyes.org.uk | Full Member |
| United Kingdom of Great Britain and Northern Ireland | Degos Disease Support Network | www.degosdisease.com | Associate member |
| United Kingdom of Great Britain and Northern Ireland | Ectodermal Dysplasia Society | www.ectodermaldysplasia.org | Full Member |
| United Kingdom of Great Britain and Northern Ireland | European Lung Foundation | www.european-lung-foundation.org/ | Associate member |
| United Kingdom of Great Britain and Northern Ireland | European Myasthenia Gravis Association | www.eumga.eu | Associate member |
| United Kingdom of Great Britain and Northern Ireland | European Tuberous Sclerosis Complex Association | www.e-tsc.eu | Full Member |
| United Kingdom of Great Britain and Northern Ireland | Fabry International Network | www.fabrynetwork.org/ | Associate member |
| United Kingdom of Great Britain and Northern Ireland | Fetal Anti Convulsant Syndrome Association | | Associate member |
| United Kingdom of Great Britain and Northern Ireland | Findacure: The Fundamental Diseases Partnership | www.findacure.org.uk | Associate member |
| United Kingdom of Great Britain and Northern Ireland | FOP Friends | www.fopfriends.com | Full member |
| United Kingdom of Great Britain and Northern Ireland | Gauchers Association UK | www.gaucher.org.uk | Full Member |
| United Kingdom of Great Britain and Northern Ireland | Genetic Alliance UK | www.geneticalliance.org.uk | Full Member |
| United Kingdom of Great Britain and Northern Ireland | International Brain Tumour Alliance | www.theibta.org | Associate member |
| United Kingdom of Great Britain and Northern Ireland | International Gaucher Alliance | www.eurogaucher.org | Full member |
| United Kingdom of Great Britain and Northern Ireland | International Niemann-Pick Disease Alliance | www.inpda.org | Full member |
| United Kingdom of Great Britain and Northern Ireland | IPOPI - International Patient Organization for Primary Immunodeficiencies | www.ipopi.org | Full Member |
| United Kingdom of Great Britain and Northern Ireland | Joining Jack | www.joiningjack.org | Full member |
| United Kingdom of Great Britain and Northern Ireland | Leber's Hereditary Optic Neuropathy Society | www.lhonsociety.org | Full member |

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| United Kingdom or Great Britain and Northern Ireland | Lymphangiomatosis & Gorham Disease Alliance Europe | www.lgda.eu | Full member |
| United Kingdom or Great Britain and Northern Ireland | Max Appeal | www.maxappeal.org.uk | Full member |
| United Kingdom or Great Britain and Northern Ireland | MEBO Research | www.meboresearch.org | Associate member |
| United Kingdom or Great Britain and Northern Ireland | Metabolic Support UK | www.metabolicsupportuk.org | Full Member |
| United Kingdom or Great Britain and Northern Ireland | MPS Society | www.mpssociety.co.uk | Full Member |
| United Kingdom or Great Britain and Northern Ireland | Myotubular Trust | www.myotubulartrust.org | Full member |
| United Kingdom or Great Britain and Northern Ireland | Newlife Foundation for Disabled Children | www.bdfnewlife.co.uk | Full Member |
| United Kingdom or Great Britain and Northern Ireland | Niemann-Pick Disease Group UK | www.npuk.org | Full Member |
| United Kingdom or Great Britain and Northern Ireland | Northern Ireland Rare Disease Partnership | www.nirdp.org.uk | Full member |
| United Kingdom or Great Britain and Northern Ireland | One in a million - Pseudomyxoma Survivor | www.pseudomyxomasurvivor.co.uk | Associate member |
| United Kingdom or Great Britain and Northern Ireland | Organisation for Anti-Convulsant Syndrome | www.oacscharity.org | Full member |
| United Kingdom or Great Britain and Northern Ireland | Pitt Hopkins UK | http://pitthopkins.org.uk/ | Full member |
| United Kingdom or Great Britain and Northern Ireland | Polycystic Kidney Disease Charity (PKDC) | www.pkdcharity.org.uk | Full member |
| United Kingdom or Great Britain and Northern Ireland | Prader Willi Syndrome Association UK | www.pwsa.co.uk | Full Member |
| United Kingdom or Great Britain and Northern Ireland | PSC Support | www.pscsupport.org.uk | Full member |
| United Kingdom or Great Britain and Northern Ireland | PTEN Research Foundation | www.ptenresearch.org | Associate member |
| United Kingdom or Great Britain and Northern Ireland | Rare Autoinflammatory Conditions Community- UK | www.raccuk.com | Associate member |
| United Kingdom or Great Britain and Northern Ireland | Rare Diseases UK | www.raredisease.org.uk | Associate member |
| United Kingdom or Great Britain and Northern Ireland | Ring 20 Research and Support UK CIO | http://ring20researchsupport.co.uk/ | Associate member |

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| United Kingdom of Great Britain and Northern Ireland | Spinal Muscular Atrophy Support UK | www.smasupportuk.org.uk | Full Member |
| United Kingdom of Great Britain and Northern Ireland | Stiff Person Support Group | www.smssupportgroup.co.uk | Full Member |
| United Kingdom of Great Britain and Northern Ireland | Sturge-Weber UK | www.sturgeweber.org.uk | Full Member |
| United Kingdom of Great Britain and Northern Ireland | The AADC Research Trust Children's Charity | www.aadcresearch.org | Full member |
| United Kingdom of Great Britain and Northern Ireland | The Aarskog Foundation | www.aarskogsyndrome.foundation.co.uk | Associate member |
| United Kingdom of Great Britain and Northern Ireland | The Chromosome 18 Registry and Research Society (Europe) | www.chromosome18eur.org | Associate member |
| United Kingdom of Great Britain and Northern Ireland | The Cure & Action for Tay-Sachs (CATS) Foundation | www.cats-foundation.org | Full member |
| United Kingdom of Great Britain and Northern Ireland | The Ehlers-Danlos Society | http://ehlers-danlos.com/ | Full member |
| United Kingdom of Great Britain and Northern Ireland | The Fragile X Society | www.fragilex.org.uk/ | Full member |
| United Kingdom of Great Britain and Northern Ireland | The Maddi Foundation | http://themaddifoundation.com/ | Associate member |
| United Kingdom of Great Britain and Northern Ireland | The PBC Foundation (UK) Ltd | www.pbcfoundation.org.uk | Associate member |
| United Kingdom of Great Britain and Northern Ireland | The Ultra Rare Diseases, Disorders & Disabilities Foundation | www.ultrarare-disease.uk | Associate member |
| United Kingdom of Great Britain and Northern Ireland | Tuberous Sclerosis Association | www.tuberous-sclerosis.org | Full Member |
| United Kingdom of Great Britain and Northern Ireland | UK Mastocytosis Support Group | www.ukmasto.co.uk | Full member |
| United Kingdom of Great Britain and Northern Ireland | Unique - The Rare Chromosome Disorder Support Group | www.rarechromo.org | Full Member |
| United Kingdom of Great Britain and Northern Ireland | United Kingdom Thalassaemia Society | www.ukts.org | Full member |
| United Kingdom of Great Britain and Northern Ireland | Uveitis Information Group | www.uveitis.net | Full member |
| United Kingdom of Great Britain and Northern Ireland | Vasculitis UK (The Vasculitis Trust) | www.vasculitis.org.uk | Full member |
| United States | Alagille Syndrome Alliance | www.alagille.org | Associate member |
| United States | Alstrom Syndrome International | www.alstrom.org | Associate member |

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| United States | APS Foundation of America, Inc (APSFA) | www.apsfa.org | Associate member |
| United States | Children's Tumor Foundation | www.ctf.org | Associate member |
| United States | Chordoma Foundation | www.chordoma.org | Associate member |
| United States | Cure PSP | www.curepsp.org | Associate member |
| United States | Cystinosis Foundation | www.cystinosisfoundation.org | Associate member |
| United States | FMD Chat | http://fmdchat.blogspot.fr/ | Associate member |
| United States | International FOXC1 Foundation | foxg1.org | Associate member |
| United States | International Pemphigus & Pemphigoid Foundation | www.pemphigus.org | Associate member |
| United States | International Waldenstrom's Macroglobulinemia Foundation | www.iwmf.com | Associate member |
| United States | MCT8-AHDS Foundation Inc. | www.mct8.info | Associate member |
| United States | Neuromuscular Disease Foundation | CureHIBM.org | Associate member |
| United States | NORD National Organization For Rare Disorders | www.rarediseases.org | Associate Member |
| United States | NTM Info & Research | www.ntminfo.org | Associate member |
| United States | PTEN Hamartoma Tumor Syndrome Foundation | www.ptenfoundation.org | Associate member |
| United States | PURA Syndrome Foundation | www.purasyndrome.org | Associate member |
| United States | The Cushing Support & Research Foundation | www.csrf.net | Associate member |
| United States | The Oxalosis & Hyperoxaluria Foundation | www.ohf.org | Associate member |
| Uruguay | Asociacion Acondroplasia Uruguay | www.acondroplasiauruguay.org | Associate member |
| Venezuela | Fundación Fura | http://fundacion-fura.mozello.com (en construcción) | Associate member |