

EURORDIS Members - March 2025

Country/Region	Organisation	Website	Membership
Albania	Shoqata e Semundjeve te Rralla / Rare Disease Association Albania	http://rda-al.com/	Associate Member
Algeria	Association Elamani pour venir en aide aux Malades souffrant de l'Anémie Héritaire		Associate Member
Andorra	Associació de Malalties Minoritàries d'Andorra	https://amma.ad/	Full Member
Argentina	Alianza Argentina de Pacientes	http://alianzapacientes.org/	Associate Member
Argentina	Federación Argentina de Enfermedades Poco Frecuentes	http://fadepof.org.ar/	Associate Member
Armenia	Doctors And Children Health Care	http://www.rambler.ru	Associate Member
Armenia	National Center for Rare Disease of Armenia	http://www.cmg.am	Associate Member
Australia	Cystic Fibrosis Australia	http://www.cysticfibrosis.org.au	Associate Member
Australia	Genetic Alliance Australia	http://www.geneticalliance.org.au	Associate Member
Australia	Genetic Support Network of Victoria	https://www.gsnv.org.au/	Associate Member
Australia	Muscular Dystrophy WA	https://www.mdwa.org.au/	Associate Member
Australia	PURA Foundation Australia	https://www.purafoundation.au/	Associate Member
Australia	Rare Voices Australia	http://www.rarevoices.org.au	Associate Member
Australia	Save our Sons	https://www.saveoursons.org.au/	Associate Member
Austria	Angelman Verein Österreich	http://www.angelman.at	Full Member
Austria	Debra International	https://www.debra-international.org	Full Member
Austria	Hand in Hand Für Tay-Sachs & Palliativkinder	http://www.tay-sachs.net	Associate Member
Austria	ICA-Österreich	http://www.ica-austria.at	Full Member
Austria	Lasst uns MDS heilen - DupMECP2	https://dupmecp2.eu/	Full Member
Austria	NF Kinder- Hilfe für Neurofibromatose- PatientInnen und Angehörige	http://www.nfkinder.at	Full Member
Austria	PH Austria - Initiative Lungenhochdruck	http://www.phaustria.org	Full Member
Austria	PHA Europe	http://www.phaeurope.org	Associate Member
Austria	Pro Rare Austria, Allianz für seltenen Erkrankungen	http://www.prorare-austria.org	Full Member
Austria	Smith-Magenis-Syndrom Österreich	https://www.smith-magenis.at/	Full Member
Austria	Usher Deafblind Forum Austria	http://www.usher-taubblind.at	Associate Member
Belarus	Belarussian Organization of Patients with MPS and other Rare Genetic	http://www.mpssociety.by	Full Member
Belgium	22Q11 Europe	https://22q11europe.org/	Associate Member
Belgium	Alpha-1 Europe Alliance asbl	https://alpha1europe.org/	Associate Member
Belgium	Alpha-1 Plus asbni	https://alpha1plus.be/	Associate Member
Belgium	ALS Liga België	http://www.alsliga.be	Full Member
Belgium	Amyloïdose Vereniging België	https://www.amybel.be/	Associate Member
Belgium	Association Belge du Syndrome de Marfan Asbl	https://www.marfan.be/	Full Member

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Belgium	Association des Patients Sclérodermiques de Belgique	https://www.sclerodermie.be/	Full Member
Belgium	Association Lupus Erythematosus	http://www.lupus-belgium.org	Full Member
Belgium	Association pour l'Information et la Recherche sur les maladies rénales	http://www.airg-belgique.org	Associate Member
Belgium	Belgische Organisatie Voor Kinderen En Volwassenen Met Een Stofwisselingsprobleem	http://www.boks.be	Full Member
Belgium	Belgische Vereniging voor Longfibrose VZW	http://www.longfibrose.org	Associate Member
Belgium	BE-TSC VZW	http://www.betsc.be	Full Member
Belgium	CF Europe	https://www.cf-europe.eu/	Full Member
Belgium	Children's Tumor Foundation Europe	https://www.ctfeurope.org/	Associate Member
Belgium	Contactgroep Myeloom en Waldenström Patiënten	http://www.cmp-vlaanderen.be	Full Member
Belgium	CURE KARS - Laia Foundation	https://www.curekars.org/	Associate Member
Belgium	Debra Belgium	http://www.debra-belgium.org	Full Member
Belgium	Euro Ataxia - European Federation of hereditary Ataxias	http://www.euroataxia.org	Full Member
Belgium	European Chromosome 11 Network	https://chromosome11.org/en/home/	Full Member
Belgium	European CMT Federation	http://www.ecmtf.org	Associate Member
Belgium	European Federation of Williams Syndrome	http://www.eurowilliams.org	Full Member
Belgium	European Haemophilia Consortium	http://www.ehc.eu	Full Member
Belgium	European Liver Patients Association	https://elpa.eu/	Associate Member
Belgium	European Myasthenia Gravis Association	https://www.eumga.eu/	Associate Member
Belgium	European Network of Gynaecological Cancer Advocacy Groups	https://engage.esgo.org/	Associate Member
Belgium	European Polio Union	https://europeanpolio.eu/	Full Member
Belgium	European Pulmonary Fibrosis Federation	http://www.eu-pff.org	Associate Member
Belgium	Eye Hope Foundation	http://www.eyehopefoundation.org	Associate Member
Belgium	Fabry International Network	https://www.fabrynetwork.org/	Associate Member
Belgium	Familial Adenomatous Polyposis Association	http://www.belgianfapa.be/fr	Associate Member
Belgium	Federation of European Scleroderma Associations	https://fesca-scleroderma.eu/	Associate Member
Belgium	FEDERG - Federation of European Associations of Patients affected by Ehlers-Danlos Syndrome	https://federgerg.org/	Full Member
Belgium	Fragile X International	https://www.fraxi.org	Full Member
Belgium	HTAP Belgique asbl	http://test.ph-vzw.be/fr_FR/	Full Member
Belgium	Ichthyose Belgique - Ichthyosis België	http://www.ichthyosis.be	Full Member
Belgium	International Federation for Spina Bifida and Hydrocephalus	http://www.ifglobal.org	Full Member
Belgium	Liver Patients International	https://liverpatientsinternational.org/	Associate Member
Belgium	Lupus Europe	http://www.lupus-europe.org	Associate Member

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Belgium	Marfan Europe Network	https://www.marfan.eu	Full Member
Belgium	Mijnlever Patiëntenvereniging Zeldzame Leverziekten vzw	https://www.mijnlever.be/	Full Member
Belgium	Myeloma Patients Europe	https://www.mpeurope.org/	Associate Member
Belgium	OIFE - Osteogenesis Imperfecta Federation Europe	http://www.oife.org	Full Member
Belgium	RaDiOrg - Rare Diseases Belgium asbl/vzw	http://www.radiorg.be	Full Member
Belgium	Rare Disorders Belgium	http://www.rd-b.be	Associate Member
Belgium	Relais 22 Asbl	http://www.relais22.be	Full Member
Belgium	Siop Europe - European Society for Paediatric Oncology	http://www.siope.eu	Associate Member
Belgium	Spierziekten Vlaanderen VZW	https://spierziektenvlaanderen.be	Full Member
Belgium	Steunpunt Kinderepilepsie vzw		Full Member
Belgium	VASCAPA Vascular Anomaly Patient Association	https://www.vascapa.org/	Full Member
Belgium	Vlaams Patiëntenplatform vzw	https://vlaamspatientenplatform.be/nl	Associate Member
Belgium	Vlaamse Vereniging voor erfelijke Bindweefselaandoeningen	http://bindweefsel.be	Full Member
Belgium	Zebrapad VZW	https://www.zebrapadvzw.be	Full Member
Benin	Albinos Sans Frontières		Associate Member
Bosnia and Herzegovina	Alliance for rare diseases of Republic of Srpska, Bosnia and Herzegovina	https://savezzarijetke.org/	Full Member
Bosnia and Herzegovina	Association of Rare Disease Patients Bosnia and Herzegovina	https://www.facebook.com/udruzenje	Full Member
Brazil	Associação Brasileira de Amiloidose Hereditária	http://www.abpar.org.br/	Associate Member
Brazil	Associação Brasileira de Enfermedades Raras	http://feberraras.wixsite.com/feber-ra	Associate Member
Brazil	Instituto Vidas Raras		Associate Member
Bulgaria	Association of Tarlov Cyst patients in Bulgaria	https://tarlov-bg.eu/	Full Member
Bulgaria	Association of the patients with respiratory failure and lung transplan	https://xn--80acal2ahwkf1m.bg/	Associate Member
Bulgaria	Bulgaria society of patients with pulmonary hypertension	http://www.bspph.net	Full Member
Bulgaria	Bulgarian Association of Moschcowitz Disease (TTP)	https://ttp-bg.eu/	Full Member
Bulgaria	Bulgarian Association Wilson Disease	https://wilsonbg.org	Full Member
Bulgaria	Bulgarian Cystic Fibrosis Association	https://lifewithcf.org/	Full Member
Bulgaria	Bulgarian Huntington Association	http://huntington.bg	Associate Member
Bulgaria	Bulgarian Lymphedema Association	https://lymphoedema-bg.org	Full Member
Bulgaria	Bulgarian National Alliance of People with Rare Diseases	https://rare-bg.com/	Associate Member
Bulgaria	FAST Bulgaria		Associate Member
Bulgaria	Nataliya Foundation	https://www.nataliyafoundation.org/	Associate Member
Bulgaria	National Association For Child Support Congenital Hypothyroidism		Associate Member

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Bulgaria	National Association of Patients With Growth Hormone Deficiency	https://www.facebook.com/Национал	Full Member
Bulgaria	National Association of Patients with Mitochondrial Diseases in Bulgaria	http://www.mitobg.com/	Full Member
Bulgaria	National Gaucher Organization	https://gaucher-bg.org/	Associate Member
Bulgaria	National Syringomyelia Association		Full Member
Bulgaria	PHA Bulgaria		Full Member
Bulgaria	Pituitary Association of Bulgaria	https://www.pituitary-bg.com/	Full Member
Bulgaria	Rare Diseases Bulgaria	https://rare.bg/	Full Member
Bulgaria	Retina Bulgaria	https://retinabulgaria.bg/	Full Member
Bulgaria	Together Fighting Sarcoma	https://sarcoma.bg/	Associate Member
Burkina Faso	Fondation Internationale Tierno et Mariam	http://www.fitima.org	Associate Member
Canada	Canadian Organization For Rare Disorders	http://www.raredisorders.ca	Associate Member
Canada	International Alliance of Dermatology Patient Organizations - GlobalSkin	https://globalskin.org/	Associate Member
Canada	Lymphoma Coalition	https://lymphomacoalition.org/	Associate Member
Canada	PVNH Support & Awareness	http://www.pvnhsupport.com	Associate Member
China	Chinese Organization for Rare Disorders	http://www.hanjianbing.org	Associate Member
China	Illness Challenge Foundation	http://www.chinaicf.org/	Associate Member
Colombia	Asociación Colombiana de Pacientes con Enfermedades de Depósito Lipídico	http://www.acopel.org	Associate Member
Colombia	Foundation Diana Garcia de Olarte for PID	http://www.fundacion-fip.org	Associate Member
Croatia	Croatian Rare Liver Foundation	https://www.rijetkebolestijetre.hr/aboniraj	Associate Member
Croatia	Debra Croatia	http://www.debra-croatia.com	Full Member
Croatia	Dravet syndrome Croatia	http://dravet-sindrom-hrvatska.hr	Associate Member
Croatia	Rare Diseases Croatia	https://rijetke-bolesti.com/	Full Member
Cyprus	Cyprus Alliance for Rare Disorders	https://raredisorderscyprus.com/	Full Member
Cyprus	Cyprus Association of Inherited Metabolic Diseases 'Aspida Zois'	http://www.aspidazois.com	Full Member
Cyprus	Pancyprian Association For Rare Genetic Diseases "Unique Smiles"	https://monadikaxamogela.org/	Full Member
Cyprus	Thalassaemia International Federation	http://www.thalassaemia.org.cy	Full Member
Cyprus	The Association of People with Primary Immunodeficiency and Friends		Full Member
Czech Republic	ADNP asociace, z.s.	https://adnpasociace.cz/	Associate Member
Czech Republic	AIPO z.s.		Associate Member
Czech Republic	ALSA z.s.	https://www.zsalsa.cz/	Associate Member
Czech Republic	Association of Atypical Parkinsonian Syndromes		Associate Member
Czech Republic	HAE Junior	https://haejunior.cz/	Associate Member

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Czech Republic	Klub Nemocnych Cystickou Fibrozou	http://www.cfklub.cz	Full Member
Czech Republic	Meta, Association of Patients with Lysosomal Storage Diseases	http://www.sdruzenimeta.cz	Full Member
Czech Republic	Narodni Sdruzeni Pku A Jinych Dmp (Czech Pku Association)	https://www.nspku.cz/	Full Member
Czech Republic	Rare Diseases Czech Republic (Ceska Asociace Pro Vzacna Onemocn	https://vzacna-onemocneni.cz/	Full Member
Czech Republic	Spolecnost pro pomoc pri Huntingtonove chorobe, z.s./Czech Hunting	http://www.huntington.cz	Associate Member
Denmark	22Q11 Danmark	http://www.22q11.dk	Full Member
Denmark	Ataksi og HSP Foreningen	http://www.sca-hsp.dk	Full Member
Denmark	Blæreekstrofiforeningens	http://www.lfmb.dk	Full Member
Denmark	CCHS Danmark	http://cchsdanmark.wordpress.com/	Associate Member
Denmark	Danish Apert Syndrome Association /Danmarks Apertforening	http://www.apertforening.dk	Full Member
Denmark	Danmarks Bloderforening / Danish Haemophilia Society	http://www.bloderforeningen.dk	Full Member
Denmark	Dansk Forening for Osteogenesis/ Danish Osteogenesis Imperfecta So	http://www.dfoi.dk	Full Member
Denmark	Ehlers-Danlos Foreningen i Danmark	http://www.ehlers-danlos.dk	Full Member
Denmark	Foreningen for Möbius Syndrom i Danmark / Moebius Syndrome Ass	https://www.moebiusyndrom.dk	Full Member
Denmark	HAE Scandinavia	https://haescan.org/	Full Member
Denmark	Ichtyosis Association in Denmark	http://www.iktyosis.dk	Full Member
Denmark	Ketotic Hypoglycemia International	http://ketotichypoglycemia.org/	Full Member
Denmark	MCADD-Foreningen	http://www.mcadd.dk	Full Member
Denmark	Porfyriforeningen Danmark - Porphyria Association Denmark	https://porfyriforeningen.dk/	Full Member
Denmark	Rare Diseases Denmark (Sjaeldne Diagnoser)	http://www.sjaeldnediagnoser.dk/	Full Member
Denmark	Rohhad Nordic	https://rohhadnordic.dk	Full Member
Denmark	Wilson Patientforeningen	http://www.wilsons.dk	Full Member
Denmark	XLH, arvelig rakitis (Hereditary Rickets Patient Association)	https://xlh-patientforeningen.dk/	Associate Member
Estonia	Estonian Prader Willi Syndrome Association	http://www.pws.ee	Full Member
Finland	Association of Cancer Patients in Finland (Suomen Syopapotilaat Ry)	http://www.syopapotilaat.fi	Full Member
Finland	Finnish Allergy, Skin and Asthma Federation	http://www.allergia.fi	Full Member
Finland	Finnish Association for Ultra-Rare Diseases	http://www.ultraharvinaiset.fi	Full Member
Finland	Finnish Association of People with Physical Disabilities	http://www.invalidiitto.fi	Full Member
Finland	Finnish Neuro Society / Neuroliitto ry	https://www.neuroliitto.fi/	Full Member
Finland	Harso-Rare Disease Alliance Finland	https://www.harso.fi/en/home/	Full Member
Finland	Harvinaiset-Verkosto - Finnish Network For Rare Diseases	http://www.harvinaiset.fi	Associate Member
Finland	Inclusion Finland KVTL, Norio Centre of Rare Diseases	https://www.tukiliitto.fi/harvinaiskesk	Full Member

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Finland	SMA Finland ry	https://smafinland.fi/	Full Member
Finland	Suomen Akustikusneurinoomayhdistys ry/Finnish Acoustic Neuroma	https://www.akustikusneurinoomayhd	Full Member
Finland	Suomen Vaskuliittiyhdistys Ry / Finnish Vasculitis Association	https://www.vaskuliittiyhdistys.fi/	Full Member
France	ACO2 Gene Association	https://aco2gene.wixsite.com/asso	Associate Member
France	afa Crohn RCH France	https://www.afa.asso.fr/	Associate Member
France	AFMKT-France	http://www.associationkystedetarlov.c	Full Member
France	AFM-Téléthon	http://www.afm-telethon.com/	Full Member
France	Agir pour la Malformation Lymphatique en Alliance	https://www.asso-amla.org/fr/	Full Member
France	All Inclusive		Associate Member
France	Alliance Maladies Rares	https://alliance-maladies-rares.org/	Full Member
France	Alliance Syndrome de Dravet	http://www.dravet.fr	Full Member
France	Amis de ADNP France	https://www.alliance-maladies-rares.o	Associate Member
France	Amyloidosis Alliance the Voice of Patients	https://www.amyloidosisalliance.org/	Associate Member
France	ASL HSP-France	https://www.asl-hsp-france.org/	Full Member
France	Ass. Internationale De Dystrophie Neuro Axonale Infantile	http://www.nbiaalliance.org	Full Member
France	Assedea	http://www.assedea.fr	Full Member
France	Association ISIS	http://www.isis-asso.com	Full Member
France	Association "Turner et Vous"	http://turneretvous.org	Full Member
France	Association AMS-ARAMISE	http://www.ams-aramise.fr	Full Member
France	Association Anémies Dyserythropoïétiques Congénitales	https://filiere-mcgre.fr/le-parcours-pai	Full Member
France	Association Bernard Pépin pour la Maladie de Wilson	https://www.abpmaladiewilson.fr/	Full Member
France	Association BPAN France	https://bpanfrance.fr/	Full Member
France	Association Contre Les Maladies Mitochondriales	http://www.association-ammi.org	Full Member
France	Association Craniopharyngiome Solidarité	http://www.cranio.fr	Full Member
France	Association des Groupes Amitié Turner	https://www.agat-turner.org/	Full Member
France	Association des Malades du Syndrome de McCune-Albright	http://www.assymcal.org	Full Member
France	Association des Malades Souffrant d'Angio Oedème par déficit en C1	http://www.amsao.fr	Full Member
France	Association des Pancréatites Chroniques Hérititaires	http://www.association-apch.org	Full Member
France	Association des Patients de la maladie de Fabry	http://www.apmf-fabry.org	Associate Member
France	Association des personnes concernées par le Tremblement Essentiel	http://www.apt.es.org	Associate Member
France	Association du Naevus Géant Congénital	http://naevus.fr	Full Member
France	Association Enfants CASK France	https://www.aecf-france.fr/	Associate Member

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France	Association Française contre l'Amylose	https://amylose.asso.fr/	Full Member
France	Association Française de Gilles de la Tourette	https://www.france-tourette.org/	Full Member
France	Association Française de La Maladie de Fanconi	https://www.fanconi.com/	Full Member
France	Association Française de l'Ataxie de Friedreich	https://www.afaf.asso.fr/	Full Member
France	Association Française de l'Ostéogénèse Imparfait	https://www.aoi.asso.fr/	Full Member
France	Association Française de Narcolepsie-Cataplexie et Hypersomnie	http://www.anc-narcolepsie.com	Full Member
France	Association Française des Dysplasies Ectodermiques	https://afde.net/	Full Member
France	Association Française des Hémophiles	http://www.afh.asso.fr	Full Member
France	Association Française des Malades atteints de Porphyries	http://www.porphyrries-patients.org	Associate Member
France	Association Française des Maladies Héritaires du Rythme Cardiaque	http://www.afmhrc.org	Full Member
France	Association Française des Syndromes d'Ehlers-Danlos	https://www.afsed.com	Full Member
France	Association Française du Gougerot-Sjögren	https://www.afgs-syndromes-secs.org	Full Member
France	Association Française du Lupus et autres Maladies Auto-Immunes	http://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 Guillain-Barré	https://syndrome-guillain-barre.fr	Full Member
France	Association Française du Syndrome de Klippel-Feil	https://afskf.fr/	Full Member
France	Association Française du Syndrome de Lowe	http://www.syndrome-lowe.org	Full Member
France	Association Française du Syndrome de Rett	https://afsr.fr/	Full Member
France	Association Française du Syndrome d'Ondine	https://afsondine.org/	Full Member
France	Association Française du Syndrome Phelan-Mcdermid	http://22q13.fr	Full Member
France	Association Française Sturge Weber "Vanille-Fraise"	http://www.vanille-fraise.org	Associate Member
France	Association France Vascularites	https://www.association-vascularites.c	Full Member
France	Association Francophone contre la Polychondrite Chronique Atrophia	http://www.afpca.fr	Associate Member
France	Association Francophone de la Maladie de Blackfan Diamond	http://afmbd.org/	Full Member
France	Association Francophone des Glycogénoses	http://www.glycogenoses.org	Full Member
France	Association Francophone du Syndrome d'Angelman	https://www.angelman-afsa.org/	Full Member
France	Association GENIRIS	https://www.geniris.fr/	Full Member
France	Association Gitelbart	https://gitelbart.fr	Full Member
France	Association Grandir	http://www.grandir.asso.fr	Full Member
France	Association Guerrier Mitochondrial	https://associationguerrie.wixsite.com	Associate Member
France	Association Histiocytose France	http://www.histiocytose.org	Full Member
France	Association Hypoparathyroidisme France	http://www.hypopara.fr	Full Member

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France	Association Ichtyose France	http://www.ichtyose.fr	Full Member
France	Association Internationale Maladies Kystes Tarlov	http://www.aimktarlov.org	Associate Member
France	Association KCNB1 France	https://kcnb1-france.org/	Full Member
France	Association Kourir	http://www.kourir.org	Full Member
France	Association Maladies du Foie depuis l'Enfance	https://amfe.fr/	Full Member
France	Association Marfans	http://www.assomarfans.fr	Full Member
France	Association Microphthalmie France	http://asso-microphthalmie.org	Full Member
France	Association Naevus 2000	https://www.naevus2000.com/	Full Member
France	Association Nationale des Cardiaques Congénitaux	http://www.ancc.asso.fr	Full Member
France	Association Neurofibromatoses & Recklinghausen	http://www.anrfrance.fr	Full Member
France	Association Noonan	http://www.assonoonan.fr/	Full Member
France	Association Ollier Maffucci Europe	http://www.olliermaffucci-asso.fr/	Full Member
France	Association Pemphigus – Pemphigoïdes France	http://www.pemphigus.asso.fr	Full Member
France	Association Polyposes Familiales	http://www.polyposes-familiales.fr	Full Member
France	Association pour aider et informer les Syringomyéliques Européens R	https://www.apaiser.org/	Full Member
France	Association pour la lutte contre l'Alcaptonurie	https://www.alcap.org	Full Member
France	Association pour la Lutte contre les maladies Inflammatoires du Foie	http://www.albi-france.org	Full Member
France	Association pour la recherche sur la Sclérose Latérale Amyotrophique	https://www.arsla.org/	Associate Member
France	Association pour la Sensibilisation aux Maladies Rares, Orphelines et	https://maladiesraresspm.simdif.com/	Full Member
France	Association pour l'aide aux personnes concernées par les Maladies Ra	http://www.amws-caps.org/	Full Member
France	Association pour l'information et la prévention de la Drépanocytose	http://www.apipd.fr	Full Member
France	Association pour l'information et la recherche sur les Maladies Rénal	http://www.airg-france.fr	Full Member
France	Association Sans Diagnostic et Unique	https://asdu.fr/	Associate Member
France	Association Sclérose Tubéreuse de Bourneville	http://www.astb.asso.fr	Full Member
France	Association SED1+	http://www.assosed1plus.com/	Full Member
France	Association SOS Desmoïde	http://www.sos-desmoide.asso.fr	Full Member
France	Association Spina Bifida et handicaps associés	http://www.spina-bifida.org	Associate Member
France	Association Surrénales	https://www.surrenales.com/	Full Member
France	Association Syndrome de Cowden	https://www.syndromedecowden.com	Full Member
France	Association syndrome de Kleine-Levin	http://kls-france.org	Full Member
France	Association Syndrome de Moebius France	https://www.moebius-france.org/	Full Member
France	Association Syndrome PACS1 - Schuurs-Hoeijmakers	https://www.pacs1.org/	Associate Member

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France	Association Tanguy Moya Moya	https://france-moya-moya.org/	Full Member
France	AVML Vivre Mieux le Lymphœdème	https://avml.fr/	Full Member
France	Charcot-Marie-Tooth France	http://www.cmt-france.org	Full Member
France	Cutis Laxa Internationale	http://www.cutislaxa.org	Full Member
France	Debra France	http://www.debra.fr	Full Member
France	Diabete Insipide France		Associate Member
France	Dravet Syndrome European Federation	https://dravet.eu/	Full Member
France	Dup15q France	https://www.dup15qfrance.fr	Full Member
France	Ectodermal Dysplasias International Network	https://edinetwork.org/	Associate Member
France	Enfants de la Lune Association pour le Xeroderma Pigmentosum	http://www.enfantsdelalune.org	Full Member
France	Ensemble Leucemie Lymphomes Espoir	https://www.elye.fr/	Full Member
France	Espoir de Noisette	https://www.association-espoirdenoisette.org/	Associate Member
France	Euro-Dyma	https://euro-dyma.eu/	Associate Member
France	European Federation for Hereditary Spastic Paraplegia	http://eurohsp.eu/	Full Member
France	European Federation Lesch-Nyhan Disease	http://www.LNDE.org	Associate Member
France	European Federation of Associations of Patients with Haemochromatosis	http://efaph.eu/	Full Member
France	European Patient Organisation for Dysimmune and Inflammatory Neuropathies	https://www.epodin.org/	Associate Member
France	EwenLife Rare Diseases	https://www.ewenlife.org/	Associate Member
France	FAST France	https://www.fastfrance.org/	Full Member
France	Fédération SOS Globi	https://sosglobi.fr/	Full Member
France	Fédération Williams France	https://williams-france.org/	Full Member
France	Fitima Europe - Fondation International Tierno et Mariam	http://www.fitima.org	Full Member
France	FOP France	http://www.fopfrance.fr	Full Member
France	Fragile X France	http://www.xfra.org	Full Member
France	France Lymphangiomeleiomyomatose	http://www.francelam.org	Full Member
France	Fructos'Amis pour la Vie	http://www.fructosamispourlavie.org/	Full Member
France	Galactosémie France	https://www.galactosemie.fr/	Full Member
France	Génération 22	http://www.generation22.fr	Full Member
France	Genespoir: Association Française des Albinismes	https://www.genespoir.org/	Full Member
France	HTaPFrance	http://www.htapfrance.com	Full Member
France	Hypophosphatasie Europe	https://hypophosphatasie-europe.org/	Full Member
France	IAROD International Association for Rare Ophthalmic Diseases	https://iarod.com/	Associate Member

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Country/Region	Organisation	Website	Membership
France	Incontinentia Pigmenti France	http://incontinentia-pigmenti.fr/	Full Member
France	Inflam'Œil	https://www.inflamoeil.org/	Full Member
France	KCNQ2 France Développement	https://kcnq2francedeveloppement.fr/	Full Member
France	La Maison 8p	https://www.lamaison8p.fr	Associate Member
France	LAMA2 France, Contre les dystrophies musculaires par déficit en méri	https://www.lama2.fr/	Full Member
France	Les Amis de Remi	http://www.lesamideremi.fr	Full Member
France	Les Petits Bourdons	http://www.lespetitsbourdons.org	Associate Member
France	Lesch-Nyhan Action	https://www.lesch-nyhan-action.org/	Full Member
France	Let's Cure ACC	https://lets cureacc.com/	Associate Member
France	LHF Espoir	https://lhfespoir.org/	Full Member
France	Ligue Nationale Contre Le Cancer	http://www.ligue-cancer.net	Full Member
France	Lupus France	http://www.lupusfrance.com/	Full Member
France	MED13L Syndrome association	https://www.med13lsyndrome.eu/	Associate Member
France	MNT Mon Poumon Mon Air	https://www.mntmonpoumonmonair.fr/	Full Member
France	Mosaïques - Association des "X Fragile"	http://www.xfragile.org	Full Member
France	Neuro IFF France et Maladies à Prions	https://neuroiffrance.my.canva.site/#	Associate Member
France	Ouvrir Les Yeux	https://www.ouvrirlesyeux.org/fr/	Full Member
France	Petit Coeur de Beurre	https://www.petitcoeurdebeurre.fr	Full Member
France	Prader Willi France	https://www.prader-willi.fr/	Full Member
France	Retina France	https://www.retina.fr/	Full Member
France	Sanfilippo Sud	https://www.sanfilippo-sud.com/	Full Member
France	SDTB, notre bataille	https://www.infos-sdtb.fr/fr/	Full Member
France	Solidarité Handicap autour des Maladies Rares	http://www.solhand-maladiesrares.org	Full Member
France	Tintamarre	https://www.asso-tintamarre.org/	Full Member
France	Union Nationale des Associations Parents et Amis Personnes Handica	https://www.unapei.org/	Associate Member
France	Union Nationale des Syndromes d'Ehlers-Danlos	http://www.unsed.org	Full Member
France	Vaincre Dunnigan	https://vaincre-dunnigan.org/	Associate Member
France	Vaincre la Mucoviscidose	https://www.vaincrelamuco.org/	Full Member
France	Vaincre La Papillomatose Respiratoire Récurrente	http://www.vaincrepr.fr	Full Member
France	Vaincre Les Maladies Lysosomales	http://www.vml-asso.org	Full Member
France	Valentin APAC - Association de Porteurs d'Anomalies Chromosomiques	https://www.valentin-apac.org	Full Member
France	VHL France	http://www.vhlfrance.org	Full Member

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Country/Region	Organisation	Website	Membership
France	Vivre sans Thyroïde	https://www.forum-thyroïde.net/	Full Member
France	White Sutton France	https://whitesuttonfrance.wixsite.com	Associate Member
France	Xtraordinaire	https://www.xtraordinaire.org	Full Member
Georgia	Georgian Alliance for Rare Diseases	https://www.facebook.com/RDGeorgia	Associate Member
Georgia	Georgian Foundation for Genetic and Rare Diseases		Full Member
Georgia	Georgian Rett syndrome and other rare diseases association	https://rettsyndrome.ge/	Associate Member
Georgia	Primary Ciliary Dyskinesia Association Georgia		Associate Member
Georgia	SCN2A Georgia		Associate Member
Germany	AHC-Deutschland e.V.	https://ahc-kids.de/	Full Member
Germany	Allianz Chronischer Seltener Erkrankungen e.V.	https://www.achse-online.de/de/	Full Member
Germany	Angelman e.V.	http://www.angelman.de	Full Member
Germany	ARVC-Selbsthilfe e.V.	https://www.arvc-selbsthilfe.org/	Full Member
Germany	BSHV für Kinder, Jugendliche und Erwachsene mit seltenen, chronisch	https://www.bshv-seltene-skelett-erkr	Full Member
Germany	Bundesverband Angeborene Gefäßfehlbildungen e.V.	http://www.angiodyplasie.de	Full Member
Germany	Bundesverband für PFFD, FFU, Fibula- und Tibiadefekte e.V.	https://bupft.de/	Associate Member
Germany	Bundesverband Kleinwüchsige Menschen und ihre Familien e.V.	http://www.bkmf.de	Full Member
Germany	Bundesverband Niere e.V.	https://www.bundesverband-niere.de/	Associate Member
Germany	Bundesverband Poliomyelitis e.V.	http://polio-selbsthilfe.de/willkommer	Full Member
Germany	Bundesverband Schilddrüsenkrebs - Ohne Schilddrüse Leben e.V.	https://www.sd-krebs.de/	Full Member
Germany	Bundesverein CDG-Syndrom e.V. / Glykokids	https://www.cdg-syndrom.de/ueber-u	Full Member
Germany	Charge Syndrom e.V.	https://www.charge-syndrom.de	Full Member
Germany	Cystinose Selbsthilfe e.V.	https://www.cystinose-selbsthilfe.de/	Full Member
Germany	Deutsche Duchenne Stiftung	https://www.duchenne-deutschland.de	Full Member
Germany	Deutsche Ehlers-Danlos Initiative e.V.	http://www.ehlers-danlos-initiative.de	Full Member
Germany	Deutsche GBS CIDP Selbsthilfe e.V.	http://gbs-selbsthilfe.org	Full Member
Germany	Deutsche Interessengemeinschaft PKU	http://www.dig-pku.de	Full Member
Germany	Deutsche Klinefelter-Syndrom Vereinigung e.V.	https://www.klinefelter.de	Full Member
Germany	Deutsche Sarkoidose Vereinigung e.V.	https://www.sarkoidose.de/	Full Member
Germany	Deutsche Syringomyelie und Chiari Malformation e.V.	http://www.deutsche-syringomyelie.de	Full Member
Germany	Deutsche Uveitis-Arbeitsgemeinschaft e.V.	http://www.duag.org	Full Member
Germany	Deutscher Verband für Kavernome (e.V.)	https://www.kavernome.de/	Associate Member
Germany	Deutschsprachige Selbsthilfegruppe für Alkaptonurie e.V.	http://www.dsaku.de	Full Member

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Country/Region	Organisation	Website	Membership
Germany	dsai e.V. - Patientenorganisation für angeborene Immundefekte	http://www.dsai.de	Full Member
Germany	Dup15q e.V.	https://dup15q.de/	Full Member
Germany	EAT – Esophageal Atresia Global support groups	http://www.we-are-eat.org	Full Member
Germany	European Congenital Heart Disease Organisation	http://echdo.eu	Associate Member
Germany	European MEN Alliance	https://www.emena.eu/	Associate Member
Germany	European Network for Ichthyosis	https://ichthyosis.info/	Full Member
Germany	Faun Stiftung	http://faun-stiftung.de	Associate Member
Germany	FOP Germany (Förderverein für an Fibrodysplasia Ossificans Progressi	http://www.fop-ev.de	Full Member
Germany	Gaucher Gesellschaft Deutschland e.V.	https://www.ggd-ev.de/	Full Member
Germany	Gesellschaft für Mukopolysaccharidosen e.V.	http://www.mps-ev.de	Full Member
Germany	Glykogenose Deutschland e.V.	https://www.glykogenose.de/de/	Full Member
Germany	HAE Vereinigung e.V. (Hereditary Angioedema)	http://www.angioedem.de	Full Member
Germany	Hand in Hand gegen Tay-Sachs und Sandhoff e.V.	http://tay-sachs-sandhoff.de/	Full Member
Germany	Hoffnungsbaum e.V. - Verein zur Förderung der Erforschung und Beh	https://www.hoffnungsbaum.de/	Full Member
Germany	HSP-Selbsthilfegruppe Deutschland e.V.	http://www.hsp-selbsthilfegruppe.de	Full Member
Germany	IEB e.V. DEBRA Deutschland	http://www.ieb-debra.de	Full Member
Germany	IMBS Alliance	https://www.imbs-alliance.org/	Associate Member
Germany	Interessengemeinschaft Fragiles-X e.V.	http://www.frax.de	Full Member
Germany	Interessengemeinschaft Hämophiler e.V.	https://www.igh.info/	Full Member
Germany	Kinder-Augen-Krebs-Stiftung	http://www.kinderaugenkrebsstiftung.de	Associate Member
Germany	Kindernetzwerk e.V.	http://www.kindernetzwerk.de	Associate Member
Germany	Kindness for Kids Foundation	http://www.kindness-for-kids.de	Associate Member
Germany	Leben mit Behcet in Deutschland	http://www.behcet-selbsthilfe.de	Associate Member
Germany	Leona e.V.	http://www.leona-ev.de	Full Member
Germany	Marfan Hilfe Deutschland e.V.	http://www.marfan.de	Associate Member
Germany	Morbus-Osler Selbsthilfe e.V.	https://www.morbus-osler.de	Full Member
Germany	MPN-Netzwerk e.V.	http://www.Mpn-netzwerk.de	Full Member
Germany	Myelitis e.V.	https://www.myelitis.de/de/	Full Member
Germany	NCL-Gruppe Deutschland e.V.	https://www.ncl-deutschland.de/	Full Member
Germany	Nephie e.V. - Selbsthilfe nephrotisches Syndrom	http://www.nephie.de	Full Member
Germany	Netzwerk Hypophysen- und Nebennierenerkrankungen e.V. - Networl	https://www.glandula-online.de	Full Member
Germany	Patienten- und Selbsthilfeorganisation für Kinder und Erwachsene mi	https://keks.org/	Full Member

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Country/Region	Organisation	Website	Membership
Germany	Patientenverband Familiäre Amyloid Polyneuropathie	https://patientenverband-fap.de/	Associate Member
Germany	PCH-Familie e.V.	https://pch-familie.de/	Full Member
Germany	Peutz-Jeghers-Germany e.V.	http://peutz-jeghers.eu	Full Member
Germany	PKD Familiäre Zystenniere e. V.	http://www.pkdcure.de	Full Member
Germany	Pro Retina Deutschland e.V.	https://www.pro-retina.de/	Associate Member
Germany	Pulmonale Hypertonie e.V.	https://www.phev.de/	Full Member
Germany	PXE Selbsthilfegruppe Deutschland e.V.	https://pxe-shg.de/	Full Member
Germany	Sanfilippo Initiative e.V.	https://sanfilippoinitiative.org/en/hor	Associate Member
Germany	Sarcoidosis Europe	https://www.sarkoidose.de/epos/	Full Member
Germany	SCN2A Germany e.V.	https://www.scn2a.de/	Full Member
Germany	Selbsthilfe EPP e.V.	https://www.epp-deutschland.de	Full Member
Germany	Selbsthilfe Ichthyose e.V.	https://www.ichthyose.de/	Full Member
Germany	Selbsthilfegruppe Ektodermale Dysplasie e.V.	http://www.ektodermale-dysplasie.de	Full Member
Germany	Selbsthilfegruppe für komplementbedingte Erkrankungen e.V.	https://www.ahus-selbsthilfe.de/	Full Member
Germany	Selbsthilfeorganisation für Menschen mit Anorektalfehlbildungen	http://www.soma-ev.de	Full Member
Germany	Sklerodermie Selbsthilfe e.V.	https://www.sklerodermie-sh.de/	Full Member
Germany	SMA Europe	https://www.sma-europe.eu/	Full Member
Germany	SSADH-Defizit e.V.	http://ssadh.wordpress.com	Associate Member
Germany	Syngap Elternhilfe e.V.	https://www.syngap.de	Full Member
Germany	Tom Wahlig Stiftung	https://www.hsp-info.de/	Full Member
Germany	Verein Ahc18+	https://www.ahc18plus.org/	Associate Member
Germany	Verein VHL (Von Hippel - Lindau) betroffener Familien e.V.	https://www.hippel-lindau.de	Full Member
Germany	Wir sind 22Q e.V.	https://www.wirsind22q.de/	Full Member
Germany	XP – Freu(n)de Mondscheinkinder	https://www.xerodermapigmentosum	Full Member
Germany	ZNM - Zusammen Stark! e. V.	https://znm-zusammenstark.org/	Associate Member
Greece	“95” - Rare Alliance Greece	http://www.rarealliance.gr	Full Member
Greece	AGORA – federation of associations for patients with rheumatic and r	https://www.agora-platform.eu/	Associate Member
Greece	Angelman syndrome Greece	https://angelman.gr/	Full Member
Greece	Association of Greek Friends for Paediatric Immunology Primary Imm	http://www.paed-anosia.gr	Associate Member
Greece	Child's Heart	http://www.kardiapaidiou.gr	Full Member
Greece	Hellenic Cystic Fibrosis Association	https://www.cysticfibrosis.gr/	Full Member
Greece	Hellenic Friedreich's Ataxia Association	https://www.hefaa.org	Full Member

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Country/Region	Organisation	Website	Membership
Greece	Hellenic League against Rheumatism	http://www.arthritis.org.gr	Associate Member
Greece	Hellenic Myasthenia Gravis Association	http://www.myasthenia.gr	Full Member
Greece	Immune Deficiency Association GALINOS	https://galinossilogos.wixsite.com/gali	Associate Member
Greece	Karkinaki Awareness for childhood and adolescent Cancer	http://www.karkinaki.gr	Associate Member
Greece	KRIKOS ZOIS Society for Patients and Friends of Patients with Inherited	http://www.krikoszois.gr	Full Member
Greece	Muscular Dystrophy Association Hellas	http://mdahellas.gr	Full Member
Greece	Panhellenic Association of Patients & Friends with Neurofibromatosis "Life With NF"		Associate Member
Greece	Panhellenic Association of Patients with Lysosomal Disorders	http://greeklysosomal.gr	Full Member
Greece	Panhellenic Heart Diseases Organisation	http://kardiopatheia.gr	Full Member
Greece	Pespa (Greek Alliance for Rare Diseases)	http://www.pespa.gr	Associate Member
Greece	Prader Willi Syndrome Association Hellas		Full Member
Greece	Pulmonary Hypertension of Greece – Hellenic Pulmonary Hypertension	https://hellenicph.org/	Associate Member
Greece	Rare Diseases Greece	https://rarediseasesgreece.com/	Associate Member
Greece	To Mellon- Association of People with Genetic Disorders	http://www.tomellon.com.gr	Full Member
Greece	Together for Life		Full Member
Greece	VHLFA Alliance in Greece	https://www.vhlgr.org/	Associate Member
Guatemala	Asociación Nacional Guatemalteca para las Enfermedades de depósito	http://angel-lisosomal.org/	Associate Member
Guatemala	Procrece	https://www.facebook.com/asociacion	Associate Member
Hong Kong, SAR of China	Joshua Hellmann Foundation for Orphan Disease	http://www.jhforphandisease.org/	Associate Member
Hungary	Hungarian Haemophilia Society - Magyar Hemofília Egyesület	http://www.mhe.hu	Full Member
Hungary	Kéregtest rendellenesség AgCC Magyarországi Alapítványa / Disorder	https://www.agykeregtest.hu/	Associate Member
Hungary	Magyarországi Mitochondriális Betegek Alapítványa	http://www.nbia.hu	Full Member
Hungary	Primer Immunhiányos Betegek Egyesülete	http://www.pibe.hu	Full Member
Hungary	Rare Diseases Hungary - HUFERDIS	http://www.rirosz.hu	Full Member
Iceland	AHC Federation of Europe	http://www.ahcfe.eu	Associate Member
Iceland	Alternating Hemiplegia of Childhood Association of Iceland	http://www.ahc.is	Full Member
Iceland	Einstök Börn - Support Group for Children with Rare Disorders	http://www.einstokborn.is	Full Member
Iceland	Gudrun's Rett Syndrome Research Trust	http://rettenglar.yolasite.com	Associate Member
Iceland	HD-Association of Iceland	https://www.huntington.is/	Full Member
India	Indian Organization for Rare Diseases	https://www.rarediseases.in/	Associate Member
India	Organization For Rare Diseases India	https://ordindia.in/	Associate Member
Iran (Islamic Republic of)	Rare Disease Foundation of Iran	http://radoir.org/fa/	Associate Member

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Country/Region	Organisation	Website	Membership
Ireland	22Q11 Ireland Support Group	http://www.22q11ireland.org	Full Member
Ireland	Alpha One Foundation	http://www.alpha1.ie	Full Member
Ireland	Barretstown Serious Fun	http://www.barretstown.org	Associate Member
Ireland	Cystic Fibrosis Ireland	http://www.cfireland.ie	Associate Member
Ireland	Cystinosis Ireland	http://cystinosis.ie	Full Member
Ireland	Cystinosis Support Network Europe	https://cystinosis-europe.eu/	Associate Member
Ireland	Debra Ireland	http://www.debraireland.org	Full Member
Ireland	European Sickle Cell Federation	https://escfederation.eu/	Associate Member
Ireland	Fighting Blindness	http://www.fightingblindness.ie	Full Member
Ireland	Friedreich's Ataxia Research Alliance Ireland	https://faraireland.eu/	Full Member
Ireland	Irish Cancer Society	http://www.cancer.ie	Associate Member
Ireland	Irish MPS Society	http://www.mpssociety.ie/wordpress/	Full Member
Ireland	Neurofibromatosis Association of Ireland	http://www.nfaireland.ie	Full Member
Ireland	Pituitary Foundation Ireland	https://www.pituitaryireland.ie/	Full Member
Ireland	Popsycle Foundation	https://www.facebook.com/Popsycle0	Associate Member
Ireland	Rare Diseases Ireland	http://rdi.ie/	Full Member
Ireland	Rare Ireland	https://www.rareireland.ie/	Associate Member
Ireland	Retina International	https://retina-international.org/	Full Member
Ireland	Sickle Cell and Thalassemia Ireland	http://www.sicklecellireland.ie	Full Member
Ireland	Spina Bifida & Hydrocephalus Paediatric Advocacy Group	https://www.sbhpag.com/	Associate Member
Ireland	The Irish Fragile X Society	http://fragilexireland.org	Full Member
Ireland	TSC Ireland	https://tscireland.org/	Full Member
Ireland	Usher syndrome Ireland	https://usherireland.org/	Associate Member
Ireland	Vasculitis Ireland Awareness	https://www.vasculitis-ia.org/	Full Member
Israel	CdLS Israeli Foundation	https://www.cdlsisrael.org.il/	Associate Member
Israel	Coalition of Rare Diseases in Israel	https://www.rdisrael.org.il	Associate Member
Israel	GRIN Disorders Research Foundation	http://www.gringn.com/	Associate Member
Israel	Israel Adult Polyglucosan Body Disease		Associate Member
Israel	Little Steps Association	https://www.littlesteps.org.il/	Associate Member
Israel	NPO for promotion of health and cure of OPMD	https://opmd.health/en/home-page-ei	Associate Member
Italy	ABC Associazione Bambini Cri Du Chat	http://www.criduchat.it	Full Member
Italy	ACAR Associazione Conto Alla Rovescia	https://www.acar-aps.org/	Full Member

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Country/Region	Organisation	Website	Membership
Italy	ACMT- Rete per la malattia di Charcot-Marie-Tooth OdV	http://www.acmt-rete.it	Full Member
Italy	Acondroplasia - Insieme Per Crescere - Onlus	http://www.acondroplasiaonlus.com	Full Member
Italy	AIBWS ODV	https://www.aibws.org	Full Member
Italy	AISAP aps	https://www.aima-child.it/	Full Member
Italy	Angeli Noonan	https://www.angelinoonan.it/	Full Member
Italy	Aniridia Italiana APS	http://www.aniridia.it/	Full Member
Italy	APS Bottega del Sorriso	https://www.apsbottegedelsorriso.it/	Full Member
Italy	Assi Gulliver - Associazione Sindrome di Sotos Italia	https://www.assigulliver.it/	Full Member
Italy	Associaione Nazionale Pemfigo/Pemfigoide	https://www.pemfigo.org/	Full Member
Italy	Associazione Famiglie COL4A1-A2 APS	http://www.col4a1.it/	Full Member
Italy	Associazione Famiglie di Soggetti con Deficit dell'Ormone della Cresci	http://www.afadoc.it	Full Member
Italy	Associazione HHT Onilde Carini APS	https://www.hht.it/	Full Member
Italy	Associazione Italiana Adrenoleucodistrofia Onlus	https://www.adrenoleucodistrofia.it/	Associate Member
Italy	Associazione Italiana Cistite Interstiziale	http://www.aici-onlus.it	Full Member
Italy	Associazione Italiana Dei Cardiopatici Congeniti Adulti - Italian Guch A	http://www.aicca.eu	Associate Member
Italy	Associazione Italiana Estrofia Vescicale-Epispadia ODV	http://www.estrofiavescicale.it	Full Member
Italy	Associazione Italiana Gaucher ODV	http://www.gaucheritalia.org	Full Member
Italy	Associazione Italiana Glicogenosi	http://www.aig-aig.it	Full Member
Italy	Associazione Italiana Laryngectomizzati	http://www.ailar.it	Associate Member
Italy	Associazione Italiana Leucodistrofie Unite	http://digilander.libero.it/ailu/	Full Member
Italy	Associazione Italiana Linfoistiocitosi Emofagocitica	https://www.aileonlus.org/	Associate Member
Italy	Associazione Italiana Malati di Alcaptonuria	https://www.aimaku.it	Full Member
Italy	Associazione Italiana Miastenia e Malattie Immunodegenerative - Am	http://www.miastenia.it	Full Member
Italy	Associazione Italiana Miastenia Onlus	http://www.viverelamiastenia.it	Full Member
Italy	Associazione Italiana Morbo di Hirschsprung	http://amorhi.org	Associate Member
Italy	Associazione Italiana Mucopolisaccaridosi e Malattie Affini	http://www.aimps.it	Full Member
Italy	Associazione Italiana Niemann Pick Onlus	http://www.niemannpick.org	Full Member
Italy	Associazione Italiana Osteogenesi Imperfetta	https://www.asitoi.org/	Full Member
Italy	Associazione Italiana per la lotta alle PHTS	http://www.ptenitalia.org	Full Member
Italy	Associazione Italiana per le Malformazioni Anorettali	https://www.aimar.eu	Full Member
Italy	Associazione Italiana Porpora Immune Trombocitopenica aps	https://www.aipit.com/	Full Member
Italy	Associazione Italiana Rene Policistico Onlus	https://www.renepolicistico.it/	Full Member

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Country/Region	Organisation	Website	Membership
Italy	Associazione Italiana Sindrome di Ehlers-Danlos	https://www.aised.it/	Full Member
Italy	Associazione Italiana Sindrome di Poland ODV	https://www.sindromedipoland.org	Full Member
Italy	Associazione Italiana Sindrome e malattia di Behçet	http://www.behcet.it	Full Member
Italy	Associazione Italiana Sindrome X Fragile	http://www.xfragile.net	Full Member
Italy	Associazione Italiana Siringomielia e Arnold Chiari	http://www.aismac.org	Full Member
Italy	Associazione Italiana Sostegno Malattie Metaboliche Ereditarie Onlus	http://www.aismme.org	Full Member
Italy	Associazione LAM Italia Onlus	http://www.lam-italia.org	Full Member
Italy	Associazione Ligure Talassemici Onlus	http://www.althonlus.org	Full Member
Italy	Associazione Malattie Rare Dell'Alta Murgia Onlus	http://www.amaram.it	Associate Member
Italy	Associazione Nazionale Angioma Cavernoso Cerebrale	https://www.anaccaps.org/	Full Member
Italy	Associazione Nazionale Malattie Rare Dermatologiche Vascolari ODV	https://www.malattierare.gov.it/assoc	Associate Member
Italy	Associazione Nazionale Persone con Malattie Reumatologiche	http://www.apmar.it	Full Member
Italy	Associazione p63 Sindrome E.E.C. International APS	http://www.sindrome-eec.it	Associate Member
Italy	Associazione per le Immunodeficienze Primitive ODV	http://www.aip-it.org	Full Member
Italy	Associazione per l'Informazione e lo Studio della Acondroplasia	https://aisac.it/	Full Member
Italy	Associazione Persone Williams Italia Onlus	http://www.apwitalia.org	Full Member
Italy	Associazione Poic e dintorni Onlus	https://www.poic-e-dintorni.org/	Full Member
Italy	Associazione S.P.R.IN.T.	https://www.associazionesprint.org/	Associate Member
Italy	Associazione Sclerosi Tuberosa	http://www.sclerosituberosa.org	Full Member
Italy	Associazione Sindrome di Alström / Italian Association for Alstrom Sy	https://www.alstrom.it/	Full Member
Italy	Associazione Sindrome Nefrosica Italia Organizzazione di Volontariatc	https://www.asnit.org	Full Member
Italy	Associazione Spina Bifida Italia	https://www.spinabifidaitalia.it/	Full Member
Italy	Associazione Studio Malattie Metaboliche Ereditarie Onlus	http://www.cometaasmme.org	Full Member
Italy	Associazione Tumori Torarici Rari Onlus	https://www.tumoritoracicirari.it/	Full Member
Italy	Associazione Veneta per la Lotta alla Talassemia	http://www.avlt.it	Full Member
Italy	CHAMP1 Foundation - Europe	https://www.champ1foundation.eu/	Associate Member
Italy	CIDP Italia Onlus	http://www.cidp.it	Full Member
Italy	Collagene Vi Italia Onlus - Col6	https://www.col6.it/	Full Member
Italy	Costello.Cfc - Associazione Italiana Sindrome Di Costello - Cardiofaci	http://www.sindromedicostello.it	Full Member
Italy	Debra Italia Onlus	http://www.debraitalia.com/	Full Member
Italy	Dravet Italia Onlus	https://www.dravet.it/	Full Member
Italy	Federazione Italiana Prader-Willi	http://www.praderwilli.it	Full Member

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Country/Region	Organisation	Website	Membership
Italy	Fondazione Alessandra Bisceglia ViVa Ale Onlus	http://www.fondazionevivaale.org	Associate Member
Italy	FOP Italia ODV	http://www.fopitalia.it/	Full Member
Italy	FSHD Italia APS	https://fshditalia.org/	Full Member
Italy	Gli Amici di Daniela	http://www.amicididaniela.it	Associate Member
Italy	Gli Equilibristi HIBM	https://www.gliequilibristi-hibm.org/	Full Member
Italy	Gruppo "Italia - Glioblastoma Multiforme - Cancro al Cervello"	https://www.facebook.com/groups/itaz	Associate Member
Italy	Gruppo Famiglie Dravet Associazione Onlus	http://www.sindromedidravet.org/	Full Member
Italy	Gruppo Familiari Beta-Sarcoglicanopatie	http://www.beta-sarcoglicanopathy.or	Full Member
Italy	Gruppo Italiano per la lotta alla Sclerodermia Onlus	http://www.sclerodermia.net	Full Member
Italy	HHT Europe	http://www.hhteurope.org	Full Member
Italy	HHT Italia APS	https://www.hhtonlus.org/	Full Member
Italy	Incontinentia Pigmenti Associazione Italiana Onlus	http://www.incontinentiapigmenti.it	Associate Member
Italy	La Strada per l'Arcobaleno	http://www.stradaperlarcobaleno.com	Full Member
Italy	Lega Italiana Ricerca Huntington	https://lirh.it/en	Full Member
Italy	Linfa Odv	https://www.linfaneurofibromatosi.co	Full Member
Italy	LND Famiglie Italiane odv	https://lesch-nyhan.eu/	Full Member
Italy	Mitocon- Insieme per lo Studio e la Cura delle Malattie Mitocondriali	http://www.mitocon.it	Associate Member
Italy	NANA ETS	https://www.nanaets.org	Full Member
Italy	Oscar's Angels Italia	https://www.oscarsangelsitalia.com/	Associate Member
Italy	PANDAS Italia APS	https://pandasitalia.it/	Full Member
Italy	Parent Project aps	http://www.parentproject.it	Full Member
Italy	PKS Italia Aps	http://www.pksitalia.org	Full Member
Italy	Rari ma speciali ODV	https://www.malattiadikawasaki.it/	Full Member
Italy	Retina Italia odv	https://www.retinaitalia.org/	Full Member
Italy	Ring 14 International	http://www.ring14.org/eng/	Full Member
Italy	Sanfilippo Fighters odv	https://www.sanfilippofighters.org/en	Full Member
Italy	SCN2A ITALIA Famiglie in Rete APS	https://scn2a-italia.it/	Full Member
Italy	SCN8A Italia	https://www.scn8a.it/#	Full Member
Italy	SOD Italia - Associazione Septo Optic Dysplasia and Other Neuroendo	http://www.soditalia.it	Full Member
Italy	Un Filo per la Vita ANAD IICB	https://www.unfiloperlavita.it	Full Member
Italy	UNIAMO- Rare Diseases Italy	http://www.uniamo.org	Full Member
Italy	Unione Italiana Ittiosi	http://www.ittiosi.it	Full Member

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Country/Region	Organisation	Website	Membership
Italy	Unione Italiana Lotta Alla Distrofia Muscolare	http://www.uildm.org/	Full Member
Italy	Unione Trapiantati Polmone - Padova ODV	https://oltrelamalattia.it/	Full Member
Italy	United Onlus	https://www.unitedonlus.org/	Full Member
Italy	Uniti per la P.I.P.O.	https://www.unitiperlapipo.it/	Associate Member
Italy	World Federation of Incontinence Patients	http://www.wfip.org	Associate Member
Italy	XPDR International Association	http://www.xlpdr.com/website/index	Associate Member
Japan	Japan Patient Association	https://nanbyo.jp/	Associate Member
Kazakhstan	Association of Support to Patients with Orphan Diseases in the Republic of Kazakhstan		Associate Member
Kazakhstan	Patients with Cancer and Rare Diseases Support Association		Associate Member
Kosovo	Rare Diseases Kosovo (Shoqata e Semundje te Rralla Kosove)	https://www.facebook.com/Shoqata-e	Associate Member
Latvia	Association of People with Special Needs "Motus Vita"	https://www.motusvita.lv/	Associate Member
Latvia	Latvian Alliance for Rare Diseases	https://retasslimibas.lv/	Full Member
Latvia	Rare Disease Association "Caladrius"	https://www.draugiem.lv/caladrius/	Associate Member
Lebanon	Lebanese Association for Neuromuscular Diseases	http://landforhope.org	Associate Member
Lithuania	Asociacija „Kraujas“	https://kraujas.lt/	Full Member
Lithuania	Rare Diseases Lithuania (Vaikų retų ligų asociacija)	http://retosligos.lt/	Associate Member
Luxembourg	Alan - Maladies Rares Luxembourg	https://www.alan.lu	Full Member
Luxembourg	EDS Lëtzebuerg a.s.b.l.	https://edsletzebuerg.lu/2/	Associate Member
Luxembourg	Een Häerz Fir Kriibskrank Kanner Asbl	http://www.kriibskrankkanner.lu	Full Member
Luxembourg	Rett Syndrome Europe	https://www.rettsyndrome.eu/	Full Member
Luxembourg	Syndrome de Marfan Luxembourg den-i.lu	https://www.den-i.lu/	Associate Member
Malaysia	Malaysia Metabolic Society	https://mms.org.my/	Associate Member
Malaysia	Malaysian Rare Disorders Society	http://www.mrds.org.my	Associate Member
Malta	National Alliance For Rare Diseases Support - Malta	http://www.rarediseasesmalta.com	Full Member
Mexico	Asociacion de Gaucher de Mexico		Associate Member
Mexico	Proyecto Pide Un Deseo Mexico lap	http://www.pideundeseo.org	Associate Member
Mexico	Red Sanfilippo	http://www.redsanfilippo.org	Associate Member
Montenegro	National Organisation for Rare Diseases Montenegro	http://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		Associate Member
Nepal	Muscular Dystrophy Organization Nepal	https://www.facebook.com/MuscularD	Associate Member

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Country/Region	Organisation	Website	Membership
Netherlands	A Different Story	https://adifferentstory.nl/	Associate Member
Netherlands	AA & PNH Contact Group Foundation	http://www.aaenpnh.nl	Full Member
Netherlands	Acanthamoeba Keratitis Eye Foundation	https://akeyefoundation.com/	Associate Member
Netherlands	ALS patiëntenvereniging (ALS Patient Association)	https://www.alspatientenvereniging.nl	Full Member
Netherlands	Amyloidose Nederland	http://amyloidose.nl	Full Member
Netherlands	Angelman Syndrome Alliance	https://angelmanalliance.org/	Full Member
Netherlands	Ataxie Vereniging Nederland	https://ataxie.nl/	Full Member
Netherlands	Bijniervereniging (Dutch Adrenal Patient Society)	http://www.nvacp.nl	Full Member
Netherlands	Childhood Cancer International	https://www.childhoodcancerinternati	Full Member
Netherlands	Chordoma Foundation Europe	https://nl.chordomafoundation.org/	Full Member
Netherlands	CMTC-OVM	http://www.cmtc.nl	Full Member
Netherlands	Cornelia de Lange Syndrome World Federation	http://www.cdlsworld.org	Full Member
Netherlands	Cure ADOA Foundation	https://adoa.eu/	Full Member
Netherlands	European Cleft Organisation	http://europeancleft.org/	Associate Member
Netherlands	European Sarcoidosis Foundation	https://sarcoidosis.eu/	Associate Member
Netherlands	European Society for Phenylketonuria	http://www.espk.org	Associate Member
Netherlands	Fabry Support & Informatie Groep Nederland	https://fabry.nl/	Full Member
Netherlands	FH Europe Foundation	https://www.fheurope.org/	Associate Member
Netherlands	Fibrodysplasia Ossificans Progressiva Stichting Nederland	https://fopstichting.nl/	Full Member
Netherlands	FSHD Europe	http://fshd-europe.info	Full Member
Netherlands	Hevas	http://www.hevas.eu	Full Member
Netherlands	International Mito Patients	http://www.mitopatients.org	Full Member
Netherlands	International Painful Bladder Foundation	https://www.painful-bladder.org/	Associate Member
Netherlands	International Porphyria Patient Network	https://porphyria.network/IPPN/	Associate Member
Netherlands	Interstitiële Cystitis Patiëntenvereniging	http://www.icpatienten.nl	Full Member
Netherlands	KAISZ - Children with a Autoimmuun or Autoinflammatory Disease	http://www.kaisz.nl	Full Member
Netherlands	LMNA Cardiac Foundation	https://www.lmnacardiac.org/	Associate Member
Netherlands	MSS (Marshall-Smith Syndrome) Research Foundation	https://marshallsmith.org/	Full Member
Netherlands	Naevus Global	https://naevusglobal.nevusnetwerk.nl/	Associate Member
Netherlands	National Association ReumaZorg Nederland	https://reumazorgnederland.nl/	Associate Member
Netherlands	Nationale Vereniging L.E. patiënten	http://www.nvle.org/	Full Member
Netherlands	Nederlands Netwerk voor Lymfoedeem en Lipoedeem	https://lymfoedeem.nl/	Associate Member

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Country/Region	Organisation	Website	Membership
Netherlands	Nederlandse Hypofyse Stichting (Dutch Pituitary Foundation)	http://www.hypofyse.nl	Full Member
Netherlands	Nederlandse Leverpatienten Vereniging	http://www.leverpatientenvereniging.nl	Full Member
Netherlands	Nederlandse Phenylketonurie Vereniging / Dutch PKU Association	https://www.pkuvereniging.nl/	Full Member
Netherlands	Nederlandse Vereniging van Hemofilie-Patiënten/Netherlands Haemc	http://www.nvhp.nl	Full Member
Netherlands	Nephceurope	http://nephceurope.eu/nc/	Associate Member
Netherlands	Neurofibromatose Vereniging Nederland	http://www.neurofibromatose.nl	Full Member
Netherlands	Nevus Netwerk Nederland	https://nevusnetwerk.nl/	Full Member
Netherlands	NF Patients United	https://www.nf-patients.eu/	Associate Member
Netherlands	Oscar Nederland	https://oscarnederland.nl/	Full Member
Netherlands	Patientenorganisatie Fibreuze Dysplasie	http://www.fibreuzedysplasie.eu	Full Member
Netherlands	Patiëntenvereniging voor Blaasextrofie Nederland	https://blaasextrofie.nl/	Full Member
Netherlands	Sarcoidose.Nl	http://www.sarcoidose.nl	Full Member
Netherlands	Spierziekten Nederland - Dutch Neuromuscular Patient Association	http://www.vsn.nl	Full Member
Netherlands	Stichting Hart4Onderzoek / Heart4Research	https://hart4onderzoek.nl/	Full Member
Netherlands	Stichting Histiocytose Nederland	https://www.histio.nl/	Full Member
Netherlands	Stichting Ijzersterk	http://www.stichtingijzersterk.nl	Associate Member
Netherlands	Stichting Kans voor PKAN Kinderen	https://kansvoorpkankinderen.nl	Full Member
Netherlands	Stichting Overdruksyndroom NL	https://sosnl.nl	Full Member
Netherlands	Stichting Pierre Robin Europe - Pierre Robin Europe Foundation	http://pierrerobineurope.com	Full Member
Netherlands	Stichting RPF Nederland / Dutch RPF Foundation	https://rpf.nl/	Full Member
Netherlands	Stichting Shwachman Diamond Syndrome Support Holland	http://www.shwachman.nl	Full Member
Netherlands	Stichting Spierkracht	https://stichtingspierkrac.wixsite.com/	Associate Member
Netherlands	Stichting SynGAP Research Fund Europe	https://www.syngapresearchfund.org/	Full Member
Netherlands	Stichting TAPS Support/ TAPS Support Foundation	https://www.stichtingtapssupport.com	Associate Member
Netherlands	Stichting Terre - Rett Syndrome Foundation	https://stichtingterre.nl/	Full Member
Netherlands	Stichting voor Afweerstoornissen	http://www.stichtingvoorafweerstoorr	Full Member
Netherlands	Stichting Zeldzame Bloedziekten	http://www.bloedziekten.nl	Associate Member
Netherlands	Thyroid Cancer Alliance	https://www.facebook.com/ThyroidCa	Full Member
Netherlands	Vasculitis Stichting	http://www.vasculitis.nl	Full Member
Netherlands	Vereniging van Ehlers Danlos Patienten	https://ehlers-danlos.nl/	Full Member
Netherlands	Vereniging voor Ichthyosis Netwerken	https://ichthyosisnetwerken.nl/	Full Member
Netherlands	VHL Europa	https://www.vhl-europa.org/	Associate Member

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Netherlands	Volwassenen, Kinderen En Stofwisselingsziekten	https://www.stofwisselingsziekten.nl/	Full Member
Netherlands	VSOP - Vereniging Samenwerkende Ouder En Patiëntenorganisaties	https://vsop.nl/	Full Member
Netherlands	World Alliance of Pituitary Organizations	http://www.wapo.org	Associate Member
Netherlands	World Duchenne Organization	https://www.worldduchenne.org/	Full Member
New Zealand	Rare Disorders NZ	http://www.nzord.org.nz	Associate Member
North Macedonia	APRDD My rare world		Associate Member
North Macedonia	Association for help and support of patients and their caregivers with	http://www.hema.org.mk	Associate Member
North Macedonia	Association for persons with Spinal Muscular Atrophy- Stop SMA	https://www.facebook.com/STOP-SMA/	Associate Member
North Macedonia	FEMINA M Skopje	http://www.feminam.org.mk/	Associate Member
North Macedonia	Life With Challenges	http://challenges.mk/?p=2288&lang=en	Full Member
North Macedonia	National Alliance For Rare Diseases of North Macedonia		Full Member
North Macedonia	Save Liver Association of Patients with Liver Diseases	https://www.facebook.com/udrugaslav/	Full Member
Norway	Aniridia Europe	http://www.aniridia.eu	Full Member
Norway	European Huntington Association	http://eurohuntington.org/	Full Member
Norway	Frambu - Resource Centre For Rare Disorders	https://frambu.no/	Full Member
Norway	HHT-Osler foreningen, Norge	http://www.osler.no	Full Member
Norway	Hjernesvulstforeningen (Norwegian Brain Tumour Association)	https://hjernesvulst.no/	Full Member
Norway	Hypopara Norge	https://www.hypopara.no/	Full Member
Norway	International Huntington Association	https://huntington-disease.org/	Associate Member
Norway	MPS-Foreningen I Norge	http://mpsforeningen.no/	Associate Member
Norway	Norsk Forening For Ehlers-Danlos Syndrom	http://www.eds-foreningen.no	Full Member
Norway	Norsk Forening for Osteogenesis Imperfecta/The Norwegian Osteoge	https://nfoi.no/	Full Member
Norway	Norsk Forening For Tuberos Sklerose	http://www.nfts.no	Full Member
Norway	Norwegian Federation of Organisations of Disabled People (Funksjons	https://www.ffo.no/	Full Member
Norway	Norwegian organisation for Prader Willis syndrome	https://www.prader-willis.no/	Full Member
Poland	3majmy sie razem - Let's get together	https://3majmysierazem.pl/	Associate Member
Poland	AGO Alliance Poland	https://www.agoresearch.org/	Associate Member
Poland	Debra Polska	http://www.debra-kd.pl/	Full Member
Poland	FAST Poland	https://www.cureangelman.pl/	Associate Member
Poland	Foundation for Leukemia Patients / Fundacji Na Rzecz Pomocy Chorym	https://fundacja.hematologiczna.org/	Associate Member
Poland	Foundation of Borys the Hero /Fundacja Bohatera Borysa	http://bohaterborys.pl/	Full Member
Poland	Fundacja Celując w Przyszłość / Aiming for the future Foundation	https://celujacwprzyszlosc.org/en	Associate Member

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Country/Region	Organisation	Website	Membership
Poland	Fundacja Jestesmy Pod Sciana / Foundation We Are Against the Wall	https://jestesmypodsciana.pl/	Full Member
Poland	Fundacja Lelka /Lelek Foundation	https://fundacjalelka.pl/	Full Member
Poland	Fundacja Sanfilippo	http://sanfilippo.org.pl/en/home/	Associate Member
Poland	Fundacja SMA (SMA Foundation Poland)	http://www.fsma.pl	Full Member
Poland	Fundacja Umiec Pomagac (Foundation For RD MPS)	http://www.umiecpomagac.org	Full Member
Poland	Krajowe Forum Orphan/National Forum Orphan	http://rzadkiechoroby.org/	Full Member
Poland	Matio Fundacji Pomocy Rodzinom I Chorym Na Mukowiscydozę/MAT	http://www.mukowiscydoza.pl	Full Member
Poland	PACS2 Research Foundation	https://www.pacs2research.org/	Full Member
Poland	Polish PKU and RD Association "Ars Vivendi"	http://www.fenyloketonuria.org	Full Member
Poland	Polish Society of MPS and Related Diseases	https://chorobyzadkie.pl/	Full Member
Poland	Polskie Stowarzyszenie Na Rzecz Osób Z AHC	http://www.stow.ahc-pl.org/	Associate Member
Poland	Polskie Stowarzyszenie Rodzin z Atrezią Przełyku / Polish Association	https://przelyczki.org.pl/	Associate Member
Poland	Rett Syndrome Poland - Ogólnopolskie Stowarzyszenie Pomocy Osob	https://rettsyndrome.pl/	Full Member
Poland	Stowarzyszenie Rodzin STXBP1	https://stxbp1.pl/	Full Member
Poland	The Dina Radziwillowa Child's Heart Foundation	https://www.sercedziecka.org.pl/	Full Member
Portugal	andLINFA Associação Nacional de Doentes Linfáticos / National Assoc	https://andlinfa.pt/	Full Member
Portugal	Associação Nacional De Displasias Ósseas	http://www.andoportugal.org	Associate Member
Portugal	Associação Nacional para Divulgar e Orientar para Combater e Enfren	http://doce.pt/wp/	Associate Member
Portugal	Associação Portuguesa CDG e Outras Doenças Metabolicas	https://www.facebook.com/SINDROM	Associate Member
Portugal	Associação Portuguesa De Charcot-Marie-Tooth	https://www.facebook.com/associacac	Full Member
Portugal	Associação Portuguesa De Insuficientes Renais	http://www.apir.org.pt	Full Member
Portugal	Associação Portuguesa de Leucemias e Linfomas	http://www.apll.org	Full Member
Portugal	Associação Portuguesa De Neuromusculares	https://apn.pt/apn/	Full Member
Portugal	Associação Portuguesa de Osteogénese Imperfeita	http://www.apoi.pt	Full Member
Portugal	Associação Sanfilippo Portugal	http://www.sanfilippoportugal.com	Full Member
Portugal	EVITA	http://www.evita cancro.org/	Associate Member
Portugal	Fedra - Federação Portuguesa De Doenças Raras	http://www.fedra.pt	Associate Member
Portugal	Liga Portuguesa contra as Doenças Reumáticas	http://www.lpcdr.org.pt	Full Member
Portugal	Oncological and Gynaecological Movement	https://mogportugal.pt/	Associate Member
Portugal	Raramente	https://raramente.org/en/	Associate Member
Portugal	Rarissimas - Associação Nacional De Deficiencias Mentais E Raras	https://rarissimas.pt/	Full Member
Portugal	RD-Portugal - União de Associações das Doenças Raras de Portugal	https://raras.pt/	Associate Member

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Republic of Moldova	AO SOS Autism	https://autismmoldova.md/	Associate Member
Republic of Moldova	Copiii Ploii	https://www.facebook.com/AO-Copiii-	Full Member
Romania	Asociatia Copilul Meu-Inima Mea	http://www.acmim.ro	Full Member
Romania	Asociatia Nationala Miastenia Gravis Romania /Romanian Myasthenia	http://www.miastenie.ro	Full Member
Romania	Asociatia Pentru Matei	https://www.pentrumatei.ro/	Full Member
Romania	Asociatia Persoanelor Cu Glicogenoza (APG Romania)	https://glicogenoza.ro/	Associate Member
Romania	Asociația Română De Cancere Rar/ Romanian Association for Rare Ca	http://www.arcrareromania.ro	Associate Member
Romania	Asociatia Romana pentru Boli Neurologice Periferice/Romanian Assoc	https://arbnp-cidp.ro/	Full Member
Romania	Asociatia Romana Spina Bifida si Hidrocefalie	https://www.facebook.com/ARSBH/	Associate Member
Romania	Asociatia Sindromul Coffin-Lowry/Coffin-Lowry Syndrome Associator	http://www.coffin-lowry.ro/	Associate Member
Romania	Asociatia Smacare	http://www.amiotrofie-spinala.ro	Full Member
Romania	Asociatia Werdnig Hoffman Awh	https://www.facebook.com/werdnigho	Full Member
Romania	Autoimmune Diseases Patients Association	http://www.apaa.ro	Associate Member
Romania	Charcot Marie Tooth Romania Association	http://www.asociatiacmt.ro	Associate Member
Romania	DMD Care	https://dmdcare.org	Full Member
Romania	Mastocytosis Support Association Romania	http://www.mastocitoza.ro	Associate Member
Romania	Neuro Move CMT Association	https://neuromovecmt.ro/	Associate Member
Romania	Romanian National Alliance for Rare Diseases	https://bolirareromania.ro/	Full Member
Romania	Romanian Prader Willi Association	http://www.apwromania.ro	Full Member
Russian Federation	Help to Cystic Fibrosis Patients		Full Member
Russian Federation	Interregional Public Organisation For Gaucher Disease	https://www.gaucher.ru/	Full Member
Russian Federation	Interregional Public Organisation of Patients with Fabry Disease "The	https://ufafabry.ru/	Full Member
Russian Federation	Inter-Regional Support Centre for Patients with Aniridia " Iris"	https://aniridia.ru/	Associate Member
Russian Federation	Look to see	https://looktosee.ru/	Full Member
Russian Federation	MPS Russia	http://www.mps-russia.org	Full Member
Russian Federation	National Association of Organization of Patient with Rare Diseases "G	https://nacgenetic.ru/	Associate Member
Russian Federation	NGO "Fragile Children"	https://osteogenez.ru/	Full Member
Russian Federation	Russian Association of Rare Diseases	https://www.rare-diseases.ru/	Full Member
Russian Federation	Russian Patient Association	https://vspru.ru/en	Associate Member
Russian Federation	Russian Rett Syndrome Asociation	https://radugaclinic.ru/	Associate Member
Russian Federation	SPIPORZ Union of patients with rare diseases and rare disease patient	https://spiporz.ru/	Associate Member
Russian Federation	The Association of Primary Immunodeficiency Patients	https://www.oppid.ru/	Full Member

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Country/Region	Organisation	Website	Membership
Rwanda	Centre Alliance for Rare Diseases	https://centre-alliance.rw/	Associate Member
Serbia	Child Rare Disease Support and Research Association Life	http://www.zivotorg.org	Associate Member
Serbia	Citizens Association "Bromologos"	https://fenilketonurija.com/	Associate Member
Serbia	DMD Serbia	http://dmdsrbija.rs/	Full Member
Serbia	Lil' Brave One (Hrabrisa)	https://www.hrabrisa.rs/en	Full Member
Serbia	Lymphoma Patients' Association	http://www.lipa.org.rs	Associate Member
Serbia	National Organization For Rare Diseases of Serbia	http://www.norbs.rs	Full Member
Singapore	Rare Disorders Society (Singapore)	https://rdss.org.sg/	Associate Member
Slovakia	Debra SR	http://www.debra-slovakia.org	Full Member
Slovakia	Organisation of Muscular Dystrophy in the Slovak Republic/Organizác	http://www.omdvsr.sk/	Full Member
Slovakia	Slovak Alliance of Rare Diseases	http://www.sazch.sk	Full Member
Slovakia	Slovak Cystic Fibrosis Association	https://www.cfasociacia.sk/	Full Member
Slovakia	Zdruzenie Ojedlinelych Genetických Ochorení	http://www.zogo.sk/	Associate Member
Slovenia	Association of Patients with Rare Eye Diseases Svetloba	https://drustvosvetloba.si/	Full Member
Slovenia	Debra Slovenia - Drustvo Debra Slovenija	https://debra-slovenia.si/	Full Member
Slovenia	Drustvo bolnikov s krvnimi boleznimi Slovenije/Association of Patient	http://www.drustvo-bkb.si	Full Member
Slovenia	EAMDA - European Alliance of Neuromuscular Disorders Associations	http://www.eamda.eu/	Full Member
Slovenia	European Foundation for SATB2-Associated Syndrome (SATB2 Europe	https://www.satb2europe.org/	Associate Member
Slovenia	Fabry Patients Association Slovenia / Društvo Bolnikov S Fabryjevo Bo	http://www.sb-sg.si	Full Member
Slovenia	Foundation of Child Neurology	http://pednevro.pedkl.si/ustanova/fou	Associate Member
Slovenia	IDefine Europe - Foundation for the Advanced Treatment of Rare Gen	https://idefine-europe.org/	Associate Member
Slovenia	Vesele nogice (Happy Feet)	http://drustvo-veselenogice.si/	Associate Member
Slovenia	Viljem Julijan Association for Children with Rare Diseases	http://viljem-julijan.si/	Full Member
Slovenia	Zavod Bernardi Ventrella	https://www.zavodbv.org/	Associate Member
South Africa	Primary Immunodeficiency Network of South Africa	https://pinsa.org.za/	Associate Member
South Africa	Rare Diseases South Africa NPC	https://www.rarediseases.co.za/	Associate Member
Spain	Acción y Cura Para Tay-Sachs	http://www.actays.org	Full Member
Spain	AHUCE - Asociación Nacional Huesos de Cristal	http://www.ahuce.org	Full Member
Spain	Alianza Española de Familias de von Hippel Lindau	http://www.alianzavhl.org	Full Member
Spain	AMAL Asociacion Madrilená de Afectados de Linfedema y Lipedema	https://www.amalmadrid.com/	Full Member
Spain	AMC - Artrogriposis Múltiple Congénita - España	https://artrogriposis.org/	Full Member
Spain	ASMD España	https://www.asmd.es/	Full Member

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Country/Region	Organisation	Website	Membership
Spain	Asociació Catalana de las Neurofibromatosis	http://www.acnefi.com/castella/gamh	Full Member
Spain	Asociacion Albi España	http://www.asociacionalbi.com/	Full Member
Spain	Asociacion Andaluza de Fibrosis Quística	http://fqandalucia.org/	Full Member
Spain	Asociación Andaluza de pacientes con Síndrome de Tourette y Trasto	http://www.tourette.es	Full Member
Spain	Asociación Atrofia del Nervio Optico de Leber	https://www.asanol.com/	Full Member
Spain	Asociación Chiari y Siringomielia del Principado de Asturias	http://www.chyspa.org	Full Member
Spain	Asociación Ciudadana de Afectados de Cistitis Intersticial	https://www.acaci.es/	Full Member
Spain	Asociación de Acondroplasia y otras Displasias Esqueléticas con Enani	https://adee.es/	Full Member
Spain	Asociación de Afectados CDKL5	https://aacdkl5.org	Full Member
Spain	Asociación de Afectados de Neurofibromatosis	http://www.neurofibromatosis.es	Full Member
Spain	Asociación de Afectados por Displasia Ectodérmica	https://displasiaectodermica.org/	Full Member
Spain	Asociacion De Enfermedades Raras D'genes	http://www.dgenes.es/	Full Member
Spain	Asociación de Epidermolisis Bullosa de España (Debra Spain)	http://www.pieldemariposa.es	Full Member
Spain	Asociación de Esclerodermia Castellon	https://www.esclerodermia.es/	Full Member
Spain	Asociación de Familiares y Afectados por Lipodistrofias	http://www.aelip.org	Full Member
Spain	Asociación de Hemoglobinuria Paroxística Nocturna	https://hpne.es/	Associate Member
Spain	Asociación de Nevus Gigante Congénito	http://asonevus.org/	Full Member
Spain	Asociación de Sarcomas Grupo Asistencial	https://www.asarga.es/	Full Member
Spain	Asociación de Síndrome de Lamb-Shaffer España	https://www.lambShaffer.es	Associate Member
Spain	Asociación de Uveítis - AUVEA	https://www.asociacionauvea.es/	Full Member
Spain	Asociación Enfermedad de Kawasaki	https://asenkawa.org/	Full Member
Spain	Asociación Española Aniridia	http://www.aniridia.es	Full Member
Spain	Asociación Española de Amiloidosis	https://www.amilo.es/	Associate Member
Spain	Asociación Española de Angioedema Familiar por Deficiencia del C1-Inhibidor	https://www.angioedema-aedaf.org	Full Member
Spain	Asociación Española de Enfermos de Glucogenosis	https://www.glucogenosis.org/	Full Member
Spain	Asociación Española de Enfermos de Pompe	http://www.asociaciondepompe.org	Associate Member
Spain	Asociación Española de Enfermos y Familiares de la Enfermedad de Gaucher	https://aeefegaucher.es/	Full Member
Spain	Asociación Española de Esclerodermia	https://esclerodermia.com	Full Member
Spain	Asociación Española de Familiares y Enfermos de Wilson	https://enfermedaddewilson.org/	Full Member
Spain	Asociación Española de Fibrodisplasia Osificante Progresiva	http://www.aefop-es.org	Full Member
Spain	Asociación Española de Fiebre Mediterranea Familiar	https://fmf.org.es/	Full Member
Spain	Asociación Española de Ictiosis	http://www.ictiosis.org	Full Member

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Country/Region	Organisation	Website	Membership
Spain	Asociación Española de Mastocitosis y Enfermedades Relacionadas	http://www.mastocitosis.com	Full Member
Spain	Asociación Española de Pacs1	http://pacs1.es/	Associate Member
Spain	Asociación Española de paraparesia espástica familiar Strümpell-Lorrain	http://www.aepef.org	Full Member
Spain	Asociación Española de Porfiria	http://www.porfiria.org	Full Member
Spain	Asociación Española de Raquitismos y Osteomalacia Heredados	https://aeryoh.org/	Associate Member
Spain	Asociación Española de Síndrome De Poland	http://www.aesip.es	Full Member
Spain	Asociación Española de Síndrome Tatton Brown Rahmna		Full Member
Spain	Asociación Española de Síndromes Compresivos Vasculares	https://www.aescov.es/	Full Member
Spain	Asociación Española de Sjögren	http://www.aesjogren.org	Full Member
Spain	Asociación Espanola deficit de Lipasa Acida Lisosomal	http://www.aelald.org	Full Member
Spain	Asociación Española del síndrome CDG	http://aescdg.com/	Associate Member
Spain	Asociación Española del Síndrome de Schaaf-Yang	https://www.aesys.org/	Full Member
Spain	Asociación HHT España	http://www.asociacionhht.org	Full Member
Spain	Asociación KIF1A España	https://kif1a.es/	Full Member
Spain	Asociación Kleefstra España	https://www.kleefstra.es/	Associate Member
Spain	Asociación Madrileña de Pacientes con Síndrome de Gille de la Tourette	https://www.ampastta.com/	Full Member
Spain	Asociación Mi Princesa Rett	https://miprincesarett.es/	Full Member
Spain	Asociación Nacional Amigos De Arnold Chiari	http://www.arnoldchiari.es/	Full Member
Spain	Asociación Nacional de Afectados por Síndromes de Ehlers Danlos e H	http://ansedh.org/	Full Member
Spain	Asociación Nacional de Dermatomiositis Juvenil	https://anadeju.org/	Full Member
Spain	Asociación Nacional de Hipertensión Pulmonar	https://hipertensionpulmonar.es/	Full Member
Spain	Asociación Nacional Síndrome de Apert y otras Craneosinostosis Sind	http://www.ansapert.org	Full Member
Spain	Asociación Retina Murcia	https://www.retinamurcia.org/	Full Member
Spain	Asociación Síndrome de Angelman	https://angelman-asa.org/	Full Member
Spain	Asociación síndrome de la persona rígida -stiffperson-sps	https://asociacionsindromepersonarigi	Full Member
Spain	Asociación Stop Sanfilippo	https://www.stopsanfilippo.org/	Associate Member
Spain	Asociación Xeroderma Pigmentosum	https://xerodermapigmentosum.es/	Full Member
Spain	Associacio Antian		Associate Member
Spain	Associacio Catalana de la Deleccio 22Q	http://www.22q.cat	Full Member
Spain	Associació d'Apràxia Ocular i Malalties Associades	http://apraxiaocular.blogspot.com	Associate Member
Spain	Associación Catalana de Enfermedades Neuromusculares	http://www.asecatalunya.com	Full Member
Spain	De Neu - Asociación De Enfermedades De Los Neurotransmisores	http://www.deneu.org	Full Member

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Country/Region	Organisation	Website	Membership
Spain	Duchenne Parent Project España	http://www.duchenne-spain.org	Full Member
Spain	Enfermedades Raras Mas Visibles	https://www.masvisibles.com/	Associate Member
Spain	European Network For Rare And Congenital Anaemias	http://www.enerca.org	Associate Member
Spain	FEDER - Federación Española de Enfermedades Raras	https://www.enfermedades-raras.org	Full Member
Spain	Federació Catalana de Malalties Minoritàries	https://www.fecamm.org/portal1/m_i	Full Member
Spain	Federacion de Asociaciones de Distrofias Hereditarias de Retina de Es	http://www.retinosifarpe.org	Full Member
Spain	Federación Española de Enfermedades Neuromusculares	http://www.asem-esp.org	Full Member
Spain	Federación Española de Familias de Cáncer Infantil	https://www.cancerinfantil.org	Full Member
Spain	Federación Española De Fibrosis Quística	http://www.fibrosis.org/	Full Member
Spain	Federación Española De Hemofilia	http://www.hemofilia.com	Full Member
Spain	Federación Española del Síndrome X Frágil	http://www.xfragil.org	Full Member
Spain	Fundació Síndrome d'Usher	https://savesightnoweurope.org/	Full Member
Spain	Fundación ALPE Acondroplasia	https://www.fundacionalpe.org	Full Member
Spain	Fundación Andrés Marcio, Niños Contra La Laminopatía	http://www.fundacionandresmarcio.o	Full Member
Spain	Fundación contra La Hipertensión Pulmonal	https://www.fchp.es/	Associate Member
Spain	Fundacion Libellas	https://fundacionlibellas.org	Associate Member
Spain	Fundación Mari Paz Jiménez Casado	https://www.fundacionmaripazjimene	Full Member
Spain	Fundación Niemann-Pick de España	http://www.fnp.es	Full Member
Spain	Fundacion Noelia, Collagen VI Deficiency Muscular Dystrophy	https://fundacionnoelia.org/	Full Member
Spain	Fundación Síndrome 5P Menos	http://www.fundacionsindrome5p.org	Full Member
Spain	Fundación Síndrome de Dravet - Dravet Syndrome Foundation	http://www.dravetfoundation.eu	Full Member
Spain	Fundacion Síndrome De West	http://www.sindromedewest.org	Full Member
Spain	Fundación Síndrome Wolf Hirschhorn 4P-	https://www.fundacion4pmenos.com	Full Member
Spain	Hipertension Pulmonar España Organizacion de Pacientes	https://hipertension-pulmonar.com/	Associate Member
Spain	Instituto de Investigación y Desarrollo Social de Enfermedades Poco F	http://www.pocofrecuentes.org	Associate Member
Spain	Menkes International Association	https://menkesinternational.com/	Full Member
Spain	MPS-LISOSOMALES España	https://mpslisosomales.org/	Full Member
Spain	Pequeños Superheroes	https://pequenossuperheroes.org/	Associate Member
Spain	SAF España	https://www.antifosfolipido.es/	Full Member
Spain	SAMS - Asociacion para la lucha contra los Síndromes Arrítmicos Rela	https://www.samsasociacion.com/	Full Member
Spain	Sense Barreres de Petrer	https://sensebarreres.es/	Associate Member
Spain	SIMA Asociación de afectados Síndrome de Marfan	http://www.marfan.es/	Full Member

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Country/Region	Organisation	Website	Membership
Sweden	Agrenska	http://www.agrenska.se	Full Member
Sweden	Aorta Dissektion Föreningen Skandinavien	https://aortadissektion.com/en/	Full Member
Sweden	DysNet	https://www.dysnet.org/	Full Member
Sweden	European Cavernoma Alliance	https://sites.google.com/cavernostang	Associate Member
Sweden	Neuroförbundet / Swedish Association Of Persons With Neurological	http://neuroforbundet.se	Associate Member
Sweden	Prader Willi Syndrome Association in Sweden	https://prader-willi.se/	Full Member
Sweden	Primär Immunbrist Organisationen	http://www.pio.nu	Full Member
Sweden	Rare Diseases Sweden (Riksförbundet Sällsynta Diagnoser)	https://www.sallsyntadiagnoser.se/	Full Member
Sweden	Svenska Marfanföreningen - Swedish Marfan Assciation	http://www.marfanforeningen.se/	Full Member
Sweden	Svenska Ödemförbundet (Swedish Association of Chronic Oedema)	https://www.svenskaodemforbundet.s	Associate Member
Sweden	Swedish Cystic Fibrosis Association	https://www.rfcf.se/	Full Member
Sweden	Swedish EDS Association (EDS Riksförbund)	https://ehlers-danlos.se/	Full Member
Sweden	Swedish MPS Society (Svenska MPS Föreningen)	https://mpsforeningen.se/	Full Member
Sweden	Thyroid Federation International	https://thyroid-fed.org/	Associate Member
Sweden	Wilhelm Foundation	https://wilhelmfoundation.org/	Full Member
Switzerland	AGO Alliance	https://argonautes.ngo	Associate Member
Switzerland	Association Enfance et Maladies Orphelines	http://www.aemo.ch	Associate Member
Switzerland	Association OrphanHealthcare, for Families with Rare Diseases	http://www.orphanhealthcare.org/	Associate Member
Switzerland	Blackswan Foundation	http://www.blackswanfoundation.ch	Associate Member
Switzerland	CML Advocates Network	http://www.cmladvocates.net	Associate Member
Switzerland	Esperare	http://www.esperare.org	Associate Member
Switzerland	FMF & AID Global Association	http://www.fmfandaid.org	Associate Member
Switzerland	Fondation Sanfilippo Suisse	https://www.fondation-sanfilippo.ch/	Associate Member
Switzerland	Fraxas - Association X Fragile Suisse	http://www.fraxas.ch	Full Member
Switzerland	HAEi - Hereditary Angioedema International Association	http://www.haei.org	Associate Member
Switzerland	HHT-Swiss	http://www.hhtswiss.org	Associate Member
Switzerland	MaRaVal – maladies rares valais – seltene krankheiten wallis.	https://www.maraval.ch/	Full Member
Switzerland	Marfan Foundation Switzerland (Marfan Stiftung Schweiz)	http://www.marfan.ch	Full Member
Switzerland	Prader Willi Syndrom Vereinigung Schweiz	https://www.prader-willi.ch/	Full Member
Switzerland	Proraris	http://www.proraris.ch	Full Member
Switzerland	Save sight now Europe	https://savesightnoweurope.org/	Associate Member
Switzerland	Schweizerische Gesellschaft Für Porphyrie	http://www.porphyrria.ch	Full Member

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Switzerland	Sjögren Europe	http://sjogreneurope.org/	Associate Member
Switzerland	SMA Schweiz	http://www.sma-schweiz.ch	Associate Member
Switzerland	Swiss FH/Schweizerische Gesellschaft für familiäre Formen der Hype	http://www.sghf.ch	Associate Member
Switzerland	Verband Angiodysplasie Schweiz	https://angiodysplasie.ch	Associate Member
Taiwan, Province of China	Taiwan Foundation for Rare Disorders	https://www.tfrd.org.tw/tfrd/	Associate Member
Turkey	DMD Aileleri Derneği (DMD Families Association)	https://www.dmdaileleri.org/	Full Member
Turkey	Duchenne Kas Hastalığı İle Mucadele Derneği	http://dmdturkiye.org/	Full Member
Turkey	Kifder	http://www.kifder.org.tr	Associate Member
Turkey	Mukopolisakkaridoz ve Benzeri Lizozomal Depo Hastaliklari Derneği /	http://www.mpsturk.org	Associate Member
Turkey	Pulmoner Hipertansiyon ve Skleroderma Hasta Derneği / PHA Turkey	http://www.pahssc.org.tr	Full Member
Turkey	Sistinozis Hastaları Derneği / Cistinosis Patients Association	https://www.sistinder.org/	Associate Member
Turkey	Türkiye SMA Foundation	https://www.sma.org.tr/	Full Member
Turkey	Yuzumle Mutluyum Derneği/Happy Faces	http://www.yuzumlemutluyum.org.tr	Associate Member
Ukraine	Charitable Foundation "Sister Dalila"	https://poryatunok.info/	Full Member
Ukraine	Charitable Foundation Zaporuka	https://zaporuka.org.ua/	Associate Member
Ukraine	Children with Spinal Muscular Atrophy, Charitable Foundation	https://csma.org.ua/	Full Member
Ukraine	Patients of Ukraine	https://patients.org.ua/en/	Associate Member
Ukraine	Pulmonary Hypertension Ukrainian Rare Disease Association	https://www.facebook.com/profile.ph	Full Member
Ukraine	Rare Diseases of Ukraine	https://www.facebook.com/orphandis	Full Member
Ukraine	Ukrainian Association Crystal People		Associate Member
Ukraine	Ukrainian Association of Help for Patients with CF	http://facebook.com/cysticfibrosisua	Full Member
Ukraine	Ukrainian Parent Project "Mio-Life"	http://miolife.org	Associate Member
United Kingdom of Great B	Acrodysostosis Support and Research	http://www.acrodysostosis.com	Associate Member
United Kingdom of Great B	Action Duchenne	http://www.actionduchenne.org	Full Member
United Kingdom of Great B	Advocacy For Neuroacanthocytosis Patients	http://www.naadvocacy.org	Associate Member
United Kingdom of Great B	AKU Society	https://www.akusociety.org	Full Member
United Kingdom of Great B	Alex The Leukodystrophy Charity	https://www.alextlc.org/	Associate Member
United Kingdom of Great B	Alport UK	http://www.alportuk.org/	Full Member
United Kingdom of Great B	Alstrom Syndrome Europe	https://www.alstrom.org.uk/as-europe	Associate Member
United Kingdom of Great B	Alstrom Syndrome UK	http://www.alstrom.org.uk	Full Member
United Kingdom of Great B	Amyloidosis UK	https://ttramylodosis.uk/	Associate Member
United Kingdom of Great B	Annabelle's Challenge	http://www.annabelleschallenge.org	Full Member

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Country/Region	Organisation	Website	Membership
United Kingdom of Great Britain	Arthur's Quest / SLC6A1 Connect UK	https://arthursquest.org/	Full Member
United Kingdom of Great Britain	Association for Glycogen Storage Disease	http://www.agsd.org.uk	Full Member
United Kingdom of Great Britain	Association for Multiple Endocrine Neoplasia Disorders	http://www.amend.org.uk	Full Member
United Kingdom of Great Britain	Ataxia UK	https://www.ataxia.org.uk/	Full Member
United Kingdom of Great Britain	Batten Disease Family Association	http://www.bdfa-uk.org.uk/	Full Member
United Kingdom of Great Britain	Beacon for Rare Diseases	https://www.rarebeacon.org/	Associate Member
United Kingdom of Great Britain	Behcet's UK	https://behcetsuk.org/	Full Member
United Kingdom of Great Britain	Brittle Bone Society	http://www.brittlebone.org	Associate Member
United Kingdom of Great Britain	Cambridge Rare Disease Network	https://www.camraredisease.org/	Associate Member
United Kingdom of Great Britain	Cancer 52	http://www.cancer52.org.uk	Associate Member
United Kingdom of Great Britain	CASK Research Foundation	https://caskresearch.org/	Full Member
United Kingdom of Great Britain	Cavernoma Alliance UK	http://www.cavernoma.org.uk	Full Member
United Kingdom of Great Britain	CDG UK	https://cdg-uk.org/	Full Member
United Kingdom of Great Britain	CDH International	https://cdhi.org/	Associate Member
United Kingdom of Great Britain	CDH UK	http://www.cdruk.org.uk/	Full Member
United Kingdom of Great Britain	CHAMP1 UK	https://champ1.uk/	Associate Member
United Kingdom of Great Britain	Child Growth Foundation	http://www.childgrowthfoundation.org	Full Member
United Kingdom of Great Britain	Child Lung Foundation	http://www.childlungfoundation.org	Associate Member
United Kingdom of Great Britain	Childhood Tumor Trust	https://www.childhoodtumourtrust.org	Full Member
United Kingdom of Great Britain	Children's Liver Disease Foundation	http://www.childliverdisease.org	Associate Member
United Kingdom of Great Britain	Ciliopathy Alliance	http://www.ciliopathyalliance.org	Full Member
United Kingdom of Great Britain	Contact A Family	http://www.cafamily.org.uk	Full Member
United Kingdom of Great Britain	CPA Research Foundation	https://www.cparfoundation.org/	Full Member
United Kingdom of Great Britain	Cure CLCN4	https://cureclcn4.org/	Associate Member
United Kingdom of Great Britain	Cure Myotonic Dystrophy UK Charity	https://www.congenitalmyotonicdystrophy.org	Full Member
United Kingdom of Great Britain	Cystinosis Foundation UK	http://www.cystinosis.org.uk	Full Member
United Kingdom of Great Britain	Dancing Eye Syndrome Support Trust	http://www.dancingeyes.org.uk	Full Member
United Kingdom of Great Britain	EOS Network Eosinophilic Diseases Charity	https://www.eosnetwork.org/	Associate Member
United Kingdom of Great Britain	European Lung Foundation	http://www.european-lung-foundation.org	Associate Member
United Kingdom of Great Britain	European Tuberous Sclerosis Complex Association	http://www.e-tsc.eu	Full Member
United Kingdom of Great Britain	Eyes on the Future	https://eyesonthefuture.org.uk/	Associate Member
United Kingdom of Great Britain	Fetal Anti Convulsant Syndrome Association		Associate Member

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Country/Region	Organisation	Website	Membership
United Kingdom of Great Britain	FOP Friends	https://www.fopfriends.com	Full Member
United Kingdom of Great Britain	Gauchers Association UK	http://www.gaucher.org.uk	Full Member
United Kingdom of Great Britain	Genetic Alliance UK	http://www.geneticalliance.org.uk	Full Member
United Kingdom of Great Britain	Glut1 Deficiency UK	http://www.glut1deficiency.org.uk	Associate Member
United Kingdom of Great Britain	HBA Support	https://www.hbasupport.org/	Associate Member
United Kingdom of Great Britain	Hope for Histi	https://www.hopeforhisti.org/	Associate Member
United Kingdom of Great Britain	Hope for Hypothalamic Hamartomas UK	http://www.hopeforhh.org	Full Member
United Kingdom of Great Britain	Huntington's Disease Youth Organisation	https://en.hdyo.org/	Full Member
United Kingdom of Great Britain	International Brain Tumour Alliance	http://www.theibta.org	Associate Member
United Kingdom of Great Britain	International Gaucher Alliance	https://gaucheralliance.org/	Full Member
United Kingdom of Great Britain	International Niemann-Pick Disease Alliance	https://www.inpda.org	Full Member
United Kingdom of Great Britain	International Patient Organization for Primary Immunodeficiencies	https://ipopi.org/	Full Member
United Kingdom of Great Britain	International Prader-Willi Syndrome Organisation	http://www.ipwso.org	Full Member
United Kingdom of Great Britain	ITP Support Association	https://www.itpsupport.org.uk	Full Member
United Kingdom of Great Britain	Joining Jack	http://www.joiningjack.org	Full Member
United Kingdom of Great Britain	Krabbe UK	https://www.krabbeuk.org/	Full Member
United Kingdom of Great Britain	Leber's Hereditary Optic Neuropathy Society	http://www.lhonsociety.org	Full Member
United Kingdom of Great Britain	LGD Alliance Europe	http://www.lgda.eu	Full Member
United Kingdom of Great Britain	Max Appeal	http://www.maxappeal.org.uk	Full Member
United Kingdom of Great Britain	Mebo Research	http://www.meboresearch.org	Associate Member
United Kingdom of Great Britain	Metabolic Support UK	https://metabolicsupportuk.org/	Full Member
United Kingdom of Great Britain	MPS Society	https://www.mpsociety.org.uk/	Full Member
United Kingdom of Great Britain	MVA Society	https://mvasociety.org/	Associate Member
United Kingdom of Great Britain	Myaware	https://www.myaware.org/	Full Member
United Kingdom of Great Britain	Myotubular Trust	http://www.myotubulartrust.org	Full Member
United Kingdom of Great Britain	Niemann-Pick UK	https://www.npuk.org/	Full Member
United Kingdom of Great Britain	Northern Ireland Rare Disease Partnership	https://dev.nirdp.org.uk/	Full Member
United Kingdom of Great Britain	Opie Jones Foundation	https://www.opiejonesfoundation.com	Associate Member
United Kingdom of Great Britain	Pathfinders Neuromuscular Alliance	https://www.pathfindersalliance.org.uk	Full Member
United Kingdom of Great Britain	PCD Research	https://pcdresearch.org/	Associate Member
United Kingdom of Great Britain	PIP-UK Poland Syndrome Support	https://pip-uk.org/	Full Member
United Kingdom of Great Britain	Pitt Hopkins UK	http://pitthopkins.org.uk/	Full Member

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Country/Region	Organisation	Website	Membership
United Kingdom of Great Britain	Polycystic Kidney Disease Charity	https://pkdcharity.org.uk	Full Member
United Kingdom of Great Britain	Pompe Support Network	https://pompe.uk/	Full Member
United Kingdom of Great Britain	PSC Support	https://pscsupport.org.uk/	Full Member
United Kingdom of Great Britain	Pseudomyxoma Survivor	http://www.pseudomyxomasurvivor.com	Associate Member
United Kingdom of Great Britain	Pten Research Foundation	https://www.ptenresearch.org/	Associate Member
United Kingdom of Great Britain	Rare Autoinflammatory Conditions Community- UK	http://www.raccuk.com	Associate Member
United Kingdom of Great Britain	Rare Disease Male Mental Health Support Group		Associate Member
United Kingdom of Great Britain	Rare Disease UK	https://geneticalliance.org.uk/	Associate Member
United Kingdom of Great Britain	Reverse Rett UK	http://www.reverserett.org.uk/	Full Member
United Kingdom of Great Britain	Ring 20 Research and Support UK CIO	http://ring20researchsupport.co.uk/	Associate Member
United Kingdom of Great Britain	Salivary Gland Cancer UK	https://www.salivaryglandcancer.uk/	Associate Member
United Kingdom of Great Britain	Schinz-Giedion Syndrome Foundation	https://sgsfoundation.org/	Associate Member
United Kingdom of Great Britain	Smile with Shiv	http://smilewithshiv.org/	Associate Member
United Kingdom of Great Britain	Stargardt's Connected	https://stargardtsconnected.org.uk/	Full Member
United Kingdom of Great Britain	Stiff Person Support Group	https://lizblows.wixsite.com/spsuk	Full Member
United Kingdom of Great Britain	Sturge-Weber UK	http://www.sturgeweber.org.uk	Full Member
United Kingdom of Great Britain	The AADC Research Trust Children's Charity	https://www.aadcresearch.org/	Full Member
United Kingdom of Great Britain	The Aarskog Foundation	http://www.aarskogsyndromefoundation.com	Associate Member
United Kingdom of Great Britain	The Children's Hyperinsulinism Charity	http://www.hyperinsulinism.co.uk	Full Member
United Kingdom of Great Britain	The Chromosome 18 Registry and Research Society (Europe)	https://chromosome18eur.org/	Associate Member
United Kingdom of Great Britain	The Cure & Action For Tay-Sachs (Cats) Foundation	http://www.cats-foundation.org	Full Member
United Kingdom of Great Britain	The ED Society	https://edsociety.co.uk/	Full Member
United Kingdom of Great Britain	The EHE Rare Cancer Charity	https://www.ehercc.org.uk/	Full Member
United Kingdom of Great Britain	The Ehlers-Danlos Society	https://www.ehlers-danlos.com/	Full Member
United Kingdom of Great Britain	The Fragile X Society	http://www.fragilex.org.uk/	Full Member
United Kingdom of Great Britain	The Maddi Foundation	https://themaddifoundation.com/	Associate Member
United Kingdom of Great Britain	The PBC Foundation (UK) Ltd	https://www.pbcfoundation.org.uk/	Associate Member
United Kingdom of Great Britain	Timothy Syndrome Alliance	https://timothysyndrome.org.uk/	Full Member
United Kingdom of Great Britain	TTPNetwork	https://www.ttpnetwork.org.uk/	Associate Member
United Kingdom of Great Britain	Tuberous Sclerosis Association	https://tuberous-sclerosis.org/	Full Member
United Kingdom of Great Britain	UK Mastocytosis Support Group	https://ukmasto.org/	Full Member
United Kingdom of Great Britain	Unique - Rare Chromosome Disorder Support Group	https://rarechromo.org/	Full Member

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United Kingdom of Great Britain	United Kingdom Thalassaemia Society	http://www.ukts.org	Full Member
United Kingdom of Great Britain	Vasculitis UK (The Vasculitis Trust)	http://www.vasculitis.org.uk	Full Member
United Kingdom of Great Britain	VHL UK/Ireland	https://vhl-uk-ireland.org	Full Member
United States of America	Alagille Syndrome Alliance	http://www.alagille.org	Associate Member
United States of America	Alstrom Syndrome International	http://www.alstrom.org	Associate Member
United States of America	APS Foundation of America, Inc	http://www.apsfa.org	Associate Member
United States of America	Association for Creatine Deficiencies	https://creatineinfo.org/	Associate Member
United States of America	BCM Families Foundation	http://www.blueconemonochromacy.com	Associate Member
United States of America	CACNA1A Foundation	https://www.cacna1a.org/	Associate Member
United States of America	CLOVES Syndrome Community	https://clovessyndrome.org/	Associate Member
United States of America	Cure LBSL	https://www.curelbsl.org	Associate Member
United States of America	Cure Mucopolysaccharidosis	https://www.curemucopolysaccharidosis.org/	Associate Member
United States of America	Cure PSP	http://www.curepsp.org	Associate Member
United States of America	Defeat MSA Alliance Defeat Multiple System Atrophy Alliance.	https://defeatmsa.org	Associate Member
United States of America	FMD Chat	http://fmdchat.blogspot.fr/	Associate Member
United States of America	GACI Global	https://gaciglobal.org	Associate Member
United States of America	GBS/CIDP Foundation International	https://www.gbs-cidp.org/	Associate Member
United States of America	Hypertrophic Olivary Degeneration Association	https://HODAssoc.org	Associate Member
United States of America	International Foxg1 Foundation	http://foxg1.org	Associate Member
United States of America	International Pemphigus & Pemphigoid Foundation	http://www.pemphigus.org	Associate Member
United States of America	International Sacral Agenesis/Caudal Regression Association	http://isacra.org/	Associate Member
United States of America	International WAGR Syndrome Association	http://wagr.org/	Associate Member
United States of America	International Waldenstrom's Macroglobulinemia Foundation	https://iwmf.com/	Associate Member
United States of America	Malan Syndrome Foundation	https://www.malansyndrome.org/	Associate Member
United States of America	MCT8-AHDS Foundation Inc.	http://www.mct8.info	Associate Member
United States of America	MitoAction	https://www.mitoaction.org/	Associate Member
United States of America	Myhre Syndrome Foundation	https://www.myhresyndrome.org/	Associate Member
United States of America	Neuromuscular Disease Foundation	https://curegnem.org/	Associate Member
United States of America	Nord National Organization for Rare Disorders	https://rarediseases.org/	Associate Member
United States of America	NTM Info & Research	https://ntminfo.org/	Associate Member
United States of America	Project 8p Foundation	https://project8p.org/	Associate Member
United States of America	PTEN Hamartoma Tumor Syndrome Foundation	http://www.ptenfoundation.org	Associate Member

EURORDIS Members - March 2025

Country/Region	Organisation	Website	Membership
United States of America	Pura Syndrome Foundation	https://purasyndrome.org/	Associate Member
United States of America	Remember The Girls	https://rememberthegirls.org/	Associate Member
United States of America	Sisters' Hope Foundation	https://sistershopefoundation.com/	Associate Member
United States of America	STXBP1 Foundation	https://www.stxbp1disorders.org/	Associate Member
United States of America	Superficial Siderosis Research Alliance	https://ssra.livingwithss.com/	Associate Member
United States of America	SYNGAP1 Foundation	https://www.syngap1foundation.org/	Associate Member
United States of America	Team Titin	https://titinmyopathy.com/	Associate Member
United States of America	The Cushing Support & Research Foundation	https://csrf.net/	Associate Member
United States of America	The Cute Syndrome Foundation	https://www.thecutesyndrome.com/	Associate Member
United States of America	The Oxalosis & Hyperoxaluria Foundation	https://ohf.org/	Associate Member
United States of America	The Snyder-Robinson Foundation	https://snyder-robinson.org/	Associate Member
United States of America	Usher Syndrome Coalition	http://www.usher-syndrome.org	Associate Member
Uruguay	Asociacion Acondroplasia Uruguay	https://www.facebook.com/acondropl	Associate Member
Uruguay	Fundacion Uruguaya para la Investigacion de las Enfermedades Raras	http://www.fupier.org/	Associate Member
Venezuela, Bolivarian Repu	Fundación Fura	https://fundacion-fura.mozello.com/	Associate Member
Zimbabwe	Child & Youth Care, Zimbabwe	http://www.cyc.org.zw/	Associate Member

Country/R Organisati Website Membersh