

EURORDIS Member Associations - January 2022



Country/Region	Name	Website	Membership
Albania	Shoqata e Semundjeve te Rralla / Rare Disease Association Albania	http://www.rda-al.com	Associate
Algeria	Association Elamani pour venir en aide aux Malades souffrant de l'Anémie Héritaire		Associate
Andorra	Associació de Malalties Minoritàries d'Andorra	https://amma.ad/	Full
Argentina	Alianza Argentina de Pacientes	http://alianzapacientes.org/	Associate
Argentina	Federación Argentina de Enfermedades Poco Frecuentes	http://fadepof.org.ar/	Associate
Armenia	Doctors And Children Health Care	http://www.rambler.ru	Associate
Armenia	Neurohereditary Diseases Charity Association	http://www.arminco.com	Associate
Australia	Cystic Fibrosis Australia	http://www.cysticfibrosis.org.au	Associate
Australia	Genetic Alliance Australia	http://www.geneticalliance.org.au	Associate
Australia	Genetic Support Network of Victoria	https://www.gsnv.org.au/	Associate
Australia	Muscular Dystrophy WA	https://www.mdwa.org.au/	Associate
Australia	Rare Voices Australia	http://www.rarevoices.org.au	Associate
Australia	Save our Sons	https://www.saveoursons.org.au/	Associate
Austria	Angelman Verein Österreich	http://www.angelman.at	Full
Austria	Debra International	http://www.debra-international.org	Full
Austria	Hand In Hand Für Tay-Sachs & Palliativkinder	http://www.tay-sachs.net	Associate
Austria	IC-Österreich	http://www.ica-austria.at	Full
Austria	NF Kinder – Verein zur Förderung der Neurofibromatoseforschung Österreich	http://www.nfkinder.at	Full
Austria	NF Patients United	http://www.nf-patients.eu	Associate
Austria	PHA Austria – Initiative Lungenhochdruck	http://www.lungenhochdruck.at	Full
Austria	PHA Europe	http://www.phaeurope.org	Associate
Austria	Pro Rare Austria, Allianz für seltenen Erkrankungen	http://www.prorare-austria.org	Associate
Austria	Smith-Magenis-Syndrom Österreich	https://www.smith-magenis.at/	Full
Austria	Usher Deafblind Forum Austria	http://www.usher-taubblind.at	Associate
Belarus	Belarussian Organization of Patients with MPS and other Rare Genetic Disorders	http://www.mpssociety.by	Full
Belgium	22Q11 Europe	https://22q11europe.org/	Associate
Belgium	Alpha-1 Plus Asbl	http://www.alpha1plus.be/	Associate
Belgium	ALS Liga België	http://www.alsliga.be	Full

Belgium	Association Belge du Syndrome de Marfan Asbl	https://www.marfan.be/	Full
Belgium	Association des Patients Sclérodermiques de Belgique	https://www.sclerodermie.be/	Full
Belgium	Association Lupus Erythematosus	http://www.lupus-belgium.org	Full
Belgium	Association pour l'Information et la Recherche sur les maladies rénales génétiques	http://www.airg-belgique.org	Associate
Belgium	Belgische Organisatie Voor Kinderen En Volwassenen Met Een Stofwisselingsziekte	http://www.boks.be	Full
Belgium	Belgische Vereniging voor Longfibrose VZW	http://www.longfibrose.org	Associate
Belgium	BE-TSC VZW	http://www.betsc.be	Full
Belgium	CF Europe	http://www.cf-europe.eu	Full
Belgium	Children's Tumor Foundation Europe	https://www.ctfeurope.org/	Associate
Belgium	Contactgroep Myeloom En Waldenström Patiënten	http://www.cmp-vlaanderen.be	Full
Belgium	Debra Belgium	http://www.debra-belgium.org	Full
Belgium	European Chromosome 11 Network	http://www.chromosome11.eu	Full
Belgium	European CMT Federation	http://www.ecmtf.org	Associate
Belgium	European Federation of Williams Syndrome	http://www.eurowilliams.org	Full
Belgium	European Haemophilia Consortium	http://www.ehc.eu	Full
Belgium	European Idiopathic Pulmonary Fibrosis & Related Disorders Federation	http://www.eu-ipff.org	Associate
Belgium	European Network For Research On Alternating Hemiplegia	http://www.enrah.net	Full
Belgium	Eye Hope Foundation	http://www.eyehopefoundation.org	Associate
Belgium	Familial Adenomatous Polyposis Association	http://www.belgianfapa.be/fr	Associate
Belgium	Federation of European Scleroderma Associations	http://www.fesca-scleroderma.eu	Associate
Belgium	FEDERG - Federation of European Associations of Patients affected by Renal Diseases	http://federg.org	Full
Belgium	HTAP Belgique asbl	http://test.ph-vzw.be/fr_FR/	Full
Belgium	Ichthyose Belgique - Ichthyosis België	http://www.ichthyosis.be	Full
Belgium	International Federation for Spina Bifida and Hydrocephalus	http://www.ifglobal.org	Full
Belgium	International Huntington Association	https://huntington-disease.org/	Associate
Belgium	Liver Patients International	https://liverpatientsinternational.org/	Associate
Belgium	Lupus Europe	http://www.lupus-europe.org	Associate
Belgium	Myeloma Patients Europe	http://www.mpeurope.org	Associate
Belgium	RaDiOrg - Rare Disease Organization Belgium ASBL/VZW	http://www.radiorg.be	Full
Belgium	Rare Disorders Belgium	http://www.rd-b.be	Associate
Belgium	Relais 22 Asbl	http://www.relais22.be	Full
Belgium	Siop Europe - European Society For Paediatric Oncology	http://www.siope.eu	Associate
Belgium	Spierziekten Vlaanderen VZW	https://spierziektenvlaanderen.be	Full
Belgium	Steunpunt Kinderepilepsie vzw	https://kinderepilepsie.be/	Full

Belgium	Vascular Anomaly Patient Association	http://www.vascapa.org	Full
Belgium	Vlaams Patiëntenplatform vzw	http://www.vlaamspatientenplatform.be	Associate
Belgium	Vlaamse PBC, PSC patiëntenvereniging Vzw	https://www.pbc-psc-aih-vlaanderen.be/	Full
Belgium	Vlaamse Vereniging voor erfelijke Bindweefselaandoeningen	http://bindweefsel.be	Full
Belgium	vzw GEN	https://www.vzw-gen.be/	Associate
Belgium	Zebrapad VZW	https://www.zebrapadvzw.be	Full
Benin	Albinos Sans Frontières		Associate
Bosnia and Herzegovina	Alliance for rare diseases of Republic of Srpska, Bosnia and Herzegovina	https://savezzarijetke.org/	Full
Brazil	Associacao Brasileira de Enfermedades Raras	http://feberraras.wixsite.com/feber-raras	Associate
Brazil	Associação Brasileira De Paramiloidose	http://www.paramiloidose.com.br	Associate
Brazil	Instituto Vidas Raras	http://www.vidasraras.org.br	Associate
Bulgaria	Association Of People Suffering By Acromegaly In Bulgaria		Associate
Bulgaria	Association of Tarlov Cyst patients in Bulgaria	http://tarlov-bg.eu/	Full
Bulgaria	Bulgarian Association Wilson Disease	https://wilsonbg.org	Full
Bulgaria	Bulgarian Cystic Fibrosis Association	http://lifewithcf.org/	Full
Bulgaria	Bulgarian Huntington Association	http://huntington.bg	Associate
Bulgaria	Bulgarian National Alliance of People with Rare Diseases	http://rare-bg.com/	Associate
Bulgaria	Nas - National Association Sarcoidosis Bulgaria	http://sarcoidosisbulgaria.alle.bg/	Full
Bulgaria	National Association For Child Support Congenital Hypothyroidism	http://www.abv.bg	Associate
Bulgaria	National Association of Patients With Growth Hormone Deficiency	https://www.facebook.com/Национална-Асоциация-на-пациентите-с-дефицит-на-растежния-хормон-1543573779219269/?fref=hovercard	Full
Bulgaria	National Assosiation of Syringomyelia		Full
Bulgaria	National Gaucher Organization	http://gaucher-bg.org/	Associate
Bulgaria	National Patients' Organisation	https://npo.bg/	Associate
Bulgaria	PHA Bulgaria	http://www.phabulgaria.eu	Full
Bulgaria	Retina Bulgaria	http://www.retinabulgaria.bg	Associate
Bulgaria	Retina International	http://www.retina-international.org	Full
Bulgaria	The Bulgarian Society of Patients with Pulmonary Hypertension	http://www.bspph.net	Full
Burkina Faso	Fondation Internationale Tierno et Mariam	http://www.fitima.org	Associate
Canada	Canadian Organization For Rare Disorders	http://www.raredisorders.ca	Associate
Canada	PVNH Support & Awareness	http://www.pvnhsupport.com	Associate
China	Chinese Organization for Rare Disorders	http://www.hanjianbing.org	Associate
China	Illness Challenge Foundation	http://www.chinaicf.org/	Associate

Colombia	Asociación Colombiana De Pacientes Con Enfermedades De Depósito Lisosomal	http://www.acopel.org	Associate
Colombia	Foundation Diana Garcia de Olarte for PID	http://www.fundacion-fip.org	Associate
Croatia	Debra Croatia	http://www.debra-croatia.com	Full
Croatia	Dravet syndrome Croatia	http://dravet-sindrom-hrvatska.hr	Associate
Croatia	Rare Diseases Croatia	https://rijetke-bolesti.com/	Full
Cyprus	Association of Patients & Friends of Imd "Aspida Zois"	http://www.aspidazois.com	Full
Cyprus	Cyprus Alliance For Rare Disorders	http://raredisorderscyprus.com/	Full
Cyprus	Cyprus Primary Immunodeficiency Association And Friends		Full
Cyprus	Pancyprian Association For Rare Genetic Diseases "Unique Smiles"	http://www.monadikaxamogela.com	Full
Cyprus	Thalassaemia International Federation	http://www.thalassaemia.org.cy	Full
Czech Republic	Association of Atypical Parkinsonian Syndromes		Associate
Czech Republic	Czech Huntington Association	http://www.huntington.cz	Associate
Czech Republic	HAE Junior	https://haejunior.cz/	Associate
Czech Republic	Klub Nemocnych Cystickou Fibrozou	http://www.cfklub.cz	Full
Czech Republic	Meta, Association of Patients with Lysosomal Storage Diseases	http://www.sdruzenimeta.cz	Full
Czech Republic	Narodni Sdruzeni Pku A Jinych Dmp (Czech Pku Association)	http://www.nspku.cz	Full
Czech Republic	Rare Diseases Czech Republic (Ceska Asociace Pro Vzacna Onemocneni)	http://www.vzacna-onemocneni.cz	Full
Denmark	22Q11 Danmark	http://www.22q11.dk	Full
Denmark	Addison Foreningen i Danmark	http://www.addison.dk	Full
Denmark	Blærekestroforeningens	http://www.lfmb.dk	Full
Denmark	CCHS Danmark	http://cchsdenmark.wordpress.com/	Associate
Denmark	Danish Apert Syndrome Association /Danmarks Apertforening	http://www.apertforening.dk	Full
Denmark	Danmarks Bloderforening / Danish Haemophilia Society	http://www.bloderforeningen.dk	Full
Denmark	Ehlers-Danlos Foreningen I Danmark	http://www.ehlers-danlos.dk	Full
Denmark	Foreningen for Ataksi / HSP	http://www.sca-hsp.dk	Full
Denmark	HAE Scandinavia	https://haescan.org/	Full
Denmark	Ichtyosis Association in Denmark	http://www.iktyosis.dk	Full
Denmark	Immun Defekt Foreningen	http://www.idf.dk	Full
Denmark	MCADD-Foreningen	http://www.mcadd.dk	Full
Denmark	Mitokondrie-Foreningen I Danmark	http://www.mitokondrie.dk/index.php	Full
Denmark	Möbius Syndrom Foreningen / Moebius Syndrome Association in Denmark	http://www.moebiussyndrom.dk	Full
Denmark	Porfyriforeningen Danmark - Porphyria Association Denmark	http://www.porfyriforeningen.dk	Full
Denmark	Rare Diseases Denmark (Sjaeldne Diagnoser)	http://www.sjaeldnediagnoser.dk/	Full

Denmark	The Danish Osteogenesis Imperfecta Society	http://www.dfoi.dk	Full
Denmark	Wilson Patientforeningen	http://www.wilsons.dk	Full
Denmark	XLH, arvelig rickets (Hereditary Rickets Patient Association)	https://xlh-patientforeningen.dk/	Associate
Estonia	Estonian Prader Willi Syndrome Association	http://www.pws.ee	Full
Finland	Association of Cancer Patients in Finland (Suomen Syöpäpotilaat Ry,)	http://www.syopapotilaat.fi	Full
Finland	Finnish Acoustic Neuroma Association	https://www.akustikusneurinoomayhdistys.com/	Full
Finland	Finnish Allergy, Skin And Asthma Federation	http://www.allergia.fi	Full
Finland	Finnish Association for Ultra-Rare Diseases	http://www.ultraharvinaiset.fi	Full
Finland	Finnish Association of People with Physical Disabilities	http://www.invalidiliitto.fi	Full
Finland	Finnish Neuro Society	http://www.ms-liitto.fi	Full
Finland	Harso-Rare Disease Alliance Finland	https://www.harso.fi/en/home/	Full
Finland	Harvinaiset-Verkosto - Finnish Network For Rare Diseases	http://www.harvinaiset.fi	Associate
Finland	Inclusion Finland Kvtl	http://www.kvtl.fi	Full
Finland	Rinnekoti Foundation, Norio Centre	http://www.rinnekoti.fi	Associate
Finland	SMA Finland ry	http://www.smafinland.fi/	Full
Finland	Suomen Vaskuliittiyhdistys Ry / Finnish Vasculitis Association	https://www.vaskuliittiyhdistys.fi/	Full
France	ACO2 Gene Association	https://aco2gene.wixsite.com/asso	Associate
France	afa Crohn RCH France	http://www.afa.asso.fr	Associate
France	AFMKT-France	http://www.associationkystedetarlov.com	Full
France	AFM-Téléthon	http://www.afm-France.org	Full
France	Agir pour la Malformation Lymphatique en Alliance	http://www.asso-amla.org	Full
France	Alliance Maladies Rares	http://www.alliance-maladies-rares.org	Full
France	Alliance Syndrome de Dravet	http://www.dravet.fr	Full
France	Amis de ADNP France	https://www.alliance-maladies-rares.org/association/amis-de-adnp-france/	Associate
France	Amyloidosis Alliance the Voice of Patients	https://www.amyloidosisalliance.org/	Associate
France	ASL HSP-France	http://www.asl-hsp-france.org	Full
France	Ass. Internationale De Dystrophie Neuro Axonale Infantile	http://www.nbiaalliance.org	Full
France	Assedea	http://www.assedea.fr	Full
France	Association ISIS	http://www.isis-asso.com	Full
France	Association "Turner et Vous"	http://turneretvous.org	Full
France	Association AMS-ARAMISE	http://www.ams-aramise.fr	Full
France	Association Anémies Dyserythroïétiques Congénitales	https://filiere-mcgre.fr/le-parcours-patients/associations-de-malades/	Full
France	Association Bernard Pépin pour la Maladie de Wilson	http://www.abpmaladiewilson.fr	Full
France	Association BPAN France	https://bpanfrance.fr/	Full

France	Association Contre Les Maladies Mitochondriales	http://www.association-ammi.org	Full
France	Association Craniopharyngiome Solidarité	http://www.cranio.fr	Full
France	Association des Groupes Amitié Turner	http://www.agat-turner.org	Full
France	Association des Malades du Syndrome de Mccune-Albright	http://www.assymcal.org	Full
France	Association des Malades Souffrant d'Angio Oedème par déficit en C1 Inhibiteur	http://www.amsao.fr	Full
France	Association des Pancréatites Chroniques Héritaires	http://www.association-apch.org	Full
France	Association des Patients de la maladie de Fabry	http://www.apmf-fabry.org	Associate
France	Association des personnes concernées par le Tremblement Essentiel	http://www.apt.es.org	Associate
France	Association du Naevus Géant Congénital	http://naevus.fr	Full
France	Association Française contre l'Amylose	http://www.amylose.asso.fr	Full
France	Association Française de La Maladie de Fanconi	http://www.fanconi.com	Full
France	Association Française de l'Ataxie de Friedreich	http://www.afaf.asso.fr/	Full
France	Association Française de l'Osteodystrophie Hereditaire d'Albright	http://www.afoha.org	Full
France	Association Française de l'Ostéogenèse Imparfait	http://www.aoi.asso.fr	Full
France	Association Française de Narcolepsie-Cataplexie et Hypersomnie	http://www.anc-narcolepsie.com	Full
France	Association Française des Dysplasies Ectodermiques	http://www.afde.net	Full
France	Association Française des Hémophiles	http://www.afh.asso.fr	Full
France	Association Française des Malades atteints de Porphyries	http://www.porphyrries-patients.org	Associate
France	Association Française des Maladies Héritaires du Rythme Cardiaque	http://www.afmhrc.org	Full
France	Association Française des Syndromes d'Ehlers-Danlos	http://www.afsed.com	Full
France	Association Française du Gougerot-Sjögren	http://www.afgs-syndromes-secs.org	Full
France	Association Française du Lupus et autres Maladies Auto-Immunes	http://www.lupusplus.com	Full
France	Association Française du Syndrome de Cornelia de Lange	http://afscdl.fr	Full
France	Association Française du Syndrome de Klippel-Feil	https://afskf.fr/	Full
France	Association Française du Syndrome de Lowe	http://www.syndrome-lowe.org	Full
France	Association Française du Syndrome de Rett	https://afsr.fr/	Full
France	Association Française du Syndrome d'Ondine	https://afsondine.org/	Full
France	Association Française du Syndrome Phelan-Mcdermid	http://22q13.fr	Full
France	Association Française Lesch-Nyhan Action	http://www.lesch-nyhan-action.org	Full
France	Association Française Niemann Pick	https://www.niemannpick-france.org/	Associate
France	Association Française pour le syndrome de Gilles de la Tourette	http://www.france-tourette.org	Full

France	Association Francaise Sturge Weber "Vanille-Fraise"	http://www.vanille-fraise.org	Associate
France	Association France Vascularites	http://www.association-vascularites.org	Full
France	Association Francophone contre la Polychondrite Chronique Atrophiante	http://www.afpca.fr	Associate
France	Association Francophone des Glycogénoses	http://www.glycogenoses.org	Full
France	Association Francophone du Syndrome d'Angelman	http://www.angelman-afsa.org	Full
France	Association Gitelbart	https://gitelbart.fr	Full
France	Association Grandir	http://www.grandir.asso.fr	Full
France	Association Hemochromatose France	http://www.hemochromatose.fr	Associate
France	Association Histiocytose France	http://www.histiocytose.org	Full
France	Association Huntington France	http://www.huntington.fr	Full
France	Association Hypoparathyroidisme France	http://www.hypopara.fr	Full
France	Association Ichtyose France	http://www.ichtyose.fr	Full
France	Association Internationale Maladies Kystes Tarlov	http://www.aimktarlov.org	Associate
France	Association Kourir	http://www.kourir.org	Full
France	Association Maladies Foie Enfants	http://www.amfe.fr/	Full
France	Association Marfans	http://www.assomarfans.fr	Full
France	Association Microphthalmie France	http://asso-microphthalmie.org	Full
France	Association Naevus 2000	http://www.naevus2000franceurope.org	Full
France	Association Nationale des Cardiaques Congénitaux	http://www.ancc.asso.fr	Full
France	Association Neurofibromatoses & Recklinghausen	http://www.anfrance.fr	Full
France	Association Ollier Maffucci Europe	http://www.olliermaffucci-asso.fr	Full
France	Association Pemphigus – Pemphigoïdes France	http://www.pemphigus.asso.fr	Full
France	Association pour aider et informer les Syringomyéliques Européens Réunis	https://www.apaiser.org/	Full
France	Association pour la lutte contre l'Alcaptonurie	http://www.alcap.fr	Full
France	Association pour la Lutte contre les maladies Inflammatoires du Foie et des voies biliaires	http://www.albi-france.org	Full
France	Association pour la recherche sur la Sclérose Latérale Amyotrophique	https://www.arsla.org/	Associate
France	Association pour la Sensibilisation aux Maladies Rares, Orphelines et Auto-immunes à Saint-Pierre-et-Miquelon	https://maladiesraresspm.simdif.com/index.html	Full
France	Association pour l'aide aux personnes concernées par les Maladies Rares Muckle Wells Syndrome et CINCA	http://www.amws-caps.org/	Full
France	Association pour l'information et la prévention de la Drépanocytose	http://www.apipd.fr	Full
France	Association pour l'information et la recherche sur les Maladies Rénales Génétiques	http://www.airg-france.fr	Full

France	Association Sans Diagnostic et Unique		Associate
France	Association Sclérose Tubéreuse de Bourneville	http://www.astb.asso.fr	Full
France	Association SED1+	http://www.assosed1plus.com/	Full
France	Association SOS Desmoïde	http://www.sos-desmoide.asso.fr	Full
France	Association Spina Bifida et handicaps associés	http://www.spina-bifida.org	Associate
France	Association Surrénales	http://www.surrenales.com	Full
France	Association syndrome de Kleine-Levin	http://kls-france.org	Full
France	Association Syndrome de Moebius France	http://www.moebius-france.org	Full
France	Association Tanguy Moya Moya	http://www.tanguy-moya-moya.org	Full
France	AVML Vivre Mieux le Lymphœdème	http://www.avml.fr/	Full
France	Charcot-Marie-Tooth France	http://www.cmt-france.org	Full
France	Cutis Laxa Internationale	http://www.cutislaxa.org	Full
France	Debra France	http://www.debra.fr	Full
France	Diabete Insipide France		Associate
France	Dravet Syndrome European Federation	http://www.dravet.eu	Full
France	Enfants de la Lune Association pour le Xeroderma Pigmentosum	http://www.enfantsdelalune.org	Full
France	Ensemble Leucemie Lymphomes Espoir	https://www.francelymphomeespoir.fr/#	Full
France	Euro-Dyma		Associate
France	European Federation for Hereditary Spastic Paraplegia	http://www.eurohsp.eu	Full
France	European Federation Lesch-Nyhan Disease	http://www.LNDE.org	Associate
France	European Federation of Associations of Patients with Haemochromatosis	http://efaph.eu/	Full
France	European Patient Organisation for Dysimmune and Inflammatory Neuropathies	https://www.epodin.org/	Associate
France	EwenLife	https://www.ewenlife.org/	Associate
France	Fédération SOS Globi	https://sosglobi.fr/	Full
France	Fédération Williams France	http://www.williams-france.org	Full
France	Fitima Europe - Fondation International Tierno et Mariam	http://www.fitima.org	Full
France	FOP France	http://www.fopfrance.fr	Full
France	Fragile X France	http://www.xfra.org	Full
France	France Lymphangiomeiomyomatose	http://www.francelam.org	Full
France	Fructos'Amis pour la Vie	http://www.fructosamispourlavie.org/	Full
France	Génération 22	http://www.generation22.fr	Full
France	Genespoir: Association Française des Albinismes	http://www.genespoir.org	Full
France	Geniris	http://associationgeniris.free.fr/	Full
France	HTaPFrance	http://www.htapfrance.com	Full
France	Hypophosphatasie Europe	http://www.hypophosphatasie.com	Full

France	Incontinentia Pigmenti France	http://incontinentia-pigmenti.fr/	Full
France	Inflam'Œil	http://www.inflamoeil.org	Full
France	La Maison 8p	https://www.lamaison8p.fr	Associate
France	Les Amis de Remi	http://www.lesamideremi.fr	Full
France	Les Petits Bourdons	http://www.lespetitsbourdons.org	Associate
France	Ligue contre la Cardiomyopathie	http://www.ligue-cardiomyopathie.com/	Associate
France	Ligue Nationale Contre Le Cancer	http://www.ligue-cancer.net	Full
France	Lupus France	http://www.lupusfrance.com/	Full
France	MED13L Syndrome association	http://www.med13syndrome.eu/	Associate
France	Mosaïques - Association Des "X Fragile"	http://www.xfragile.org	Full
France	Naevus Global	http://www.naevusglobal.org	Associate
France	Ouvrir Les Yeux	http://www.ouvrirlesyeux.org	Full
France	Petit Coeur de Beurre	https://www.petitcoeurdebeurre.fr/page/43746-l-association	Full
France	Polyposes Familiales - APTEPF	http://www.polyposes-familiales.fr	Full
France	Prader Willi France	http://www.prader-willi.fr	Full
France	Retina France	http://www.retina.fr	Full
France	Sanfilippo Sud	https://www.facebook.com/sanfilipposud/	Full
France	Solidarité Handicap autour des Maladies Rares	http://www.solhand-maladiesrares.org	Full
France	Syndrome PACS1 - Schuurs-Hoeijmakers	http://www.pacs1.org/	Associate
France	Tintamarre	https://www.helloasso.com/associations/association-tintamarre	Full
France	Union Huntington Espoir	http://www.huntington.asso.fr	Full
France	Union Nationale des Associations Parents et Amis Personnes Handicapées Mentales	http://www.unapei.org	Associate
France	Union Nationale des Syndromes d'Ehlers-Danlos	http://www.unsed.org	Full
France	Vaincre la Mucoviscidose	http://www.vaincrelamuco.org	Full
France	Vaincre La Papillomatose Respiratoire Récurrente	http://www.vaincreprrr.fr	Full
France	Vaincre Les Maladies Lysosomales	http://www.vml-asso.org	Full
France	Valentin APAC - Association de Porteurs d'Anomalies Chromosomiques	http://www.valentin-apac.org	Full
France	VHL France	http://www.vhlfrance.org	Full
France	Vivre sans Thyroïde	https://www.forum-thyroïde.net/	Full
France	White Sutton France	https://whitesuttonfrance.wixsite.com/	Associate
France	Xtraordinaire	http://www.xtraordinaire.org	Full
Georgia	Georgian Foundation for Genetic and Rare Diseases		Full
Georgia	SCN2A Georgia		Associate
Germany	AHC-Deutschland e.V.	http://www.ahckids.de	Full

Germany	Allianz Chronischer Seltener Erkrankungen e.V.	http://www.achse-online.de	Full
Germany	Angelman e.V.	http://www.angelman.de	Full
Germany	ARVC-Selbsthilfe e.V.	http://www.arvc-selbsthilfe.org	Full
Germany	Asociatia Romana Spina Bifida si Hidrocefalie	https://www.facebook.com/ARSBH/	Associate
Germany	BSHV für Kinder, Jugendliche und Erwachsene mit seltenen,chronischen Skeletterkrankungen e.V.	http://bshv-seltene-skelett-erkrankungen.com	Full
Germany	Bundesverband Angeborene Gefäßfehlbildungen e.V.	http://www.angiodysplasie.de	Full
Germany	Bundesverband der Clusterkopfschmerzen-Selbsthilfe-Gruppen	http://www.clusterkopf.de	Full
Germany	Bundesverband für PFFD, FFU, Fibula- und Tibiadefekte e.V.	https://bupft.de/	Associate
Germany	Bundesverband Kleinwüchsige Menschen und ihre Familien e.V.	http://www.bkmf.de	Full
Germany	Bundesverband Poliomyelitis e.V.	http://polio-selbsthilfe.de/willkommen	Full
Germany	Bundesverband Schilddrüsenkrebs - Ohne Schilddrüse Leben e.V.	https://www.sd-krebs.de/	Full
Germany	Charge Syndrom e.V.	http://www.charge-syndrom.de	Full
Germany	Cholesterin & Co e.V.	http://cholco.org	Associate
Germany	CRPS Bundesverband Deutschland e.V.	https://crps-netzwerk.org/cms/	Full
Germany	Cystinose Selbsthilfe e.V.	http://www.leben-eben.com	Full
Germany	Deutsche Duchenne Stiftung	https://www.duchenne-deutschland.de/	Full
Germany	Deutsche Ehlers-Danlos Initiative e.V.	http://www.ehlers-danlos-initiative.de	Full
Germany	Deutsche GBS CIDP Selbsthilfe e.V.	http://gbs-selbsthilfe.org	Full
Germany	Deutsche Interessengemeinschaft PKU	http://www.dig-pku.de	Full
Germany	Deutsche Klinefelter-Syndrom Vereinigung e.V.	http://www.klinefelter.de	Full
Germany	Deutsche Sarkoidose Vereinigung e.V.	http://www.Sarkoidose.de	Full
Germany	Deutsche Syringomyelie und Chiari Malformation DSCM e.V.	http://www.deutsche-syringomyelie.de	Full
Germany	Deutsche Uveitis-Arbeitsgemeinschaft e.V.	http://www.duag.org	Full
Germany	Deutschsprachige Selbsthilfegruppe für Alkaptonurie e.V.	http://www.dsaku.de	Full
Germany	we are e.v. - Patientenorganisation für angeborene Immundefekte	http://www.dsai.de	Full
Germany	Dup15q e.V.	https://dup15q.de/	Full
Germany	Esophageal Atresia Global Support Groups	http://www.we-are-eat.org	Full
Germany	European Association of Patient Organisations of Sarcoidosis	http://www.sarcoidosis.biz	Full
Germany	European MEN Alliance	http://www.Emena.eu	Associate
Germany	European Network for Ichthyosis	http://www.ichthyose.de/europa/	Full
Germany	Faun Stiftung	http://faun-stiftung.de	Associate
Germany	FOP Germany (Förderverein für an Fibrodysplasia Ossificans Progressiva Erkrankte)	http://www.fop-ev.de	Full
Germany	FSHD Europe	http://fshd-europe.info	Full
Germany	Fundacja Sanfilippo	http://sanfilippo.org.pl/en/home/	Associate

Germany	Gaucher Gesellschaft Deutschland e.V.	http://www.ggd-ev.de	Full
Germany	Gesellschaft für Mukopolysaccharidosen e.V.	http://www.mps-ev.de	Full
Germany	HAE Vereinigung e.V. (Hereditary Angioedema)	http://www.angioedem.de	Full
Germany	Hand in Hand gegen Tay-Sachs und Sandhoff e.V.	http://tay-sachs-sandhoff.de/	Full
Germany	Hoffnungsbaum e.V. - Verein zur Förderung der Erforschung und Behandlung von NBIA-Erkrankungen	http://www.hoffnungsbaum.de	Full
Germany	HSP-Selbsthilfegruppe Deutschland e.V.	http://www.hsp-selbsthilfegruppe.de	Full
Germany	IEB e.V. DEBRA Deutschland	http://www.ieb-debra.de	Full
Germany	IMBS Alliance	https://www.imbs-alliance.org/	Associate
Germany	Interessengemeinschaft Fragiles-X e.V.	http://www.frax.de	Full
Germany	Kinder mit Deletionssyndrom 22Q11 e.V.	http://www.kids-22q11.de	Full
Germany	Kinder-Augen-Krebs-Stiftung	http://www.kinderaugenkrebsstiftung.de	Associate
Germany	Kindernetzwerk e.V.	http://www.kindernetzwerk.de	Associate
Germany	Kindness for Kids Foundation	http://www.kindness-for-kids.de	Associate
Germany	Leben mit Behcet in Deutschland	http://www.behcet-selbsthilfe.de	Associate
Germany	Leona e.V.	http://www.leona-ev.de	Full
Germany	Marfan Hilfe Deutschland e.V.	http://www.marfan.de	Associate
Germany	Morbus-Osler Selbsthilfe e.V.	http://www.morbus-osler.de	Full
Germany	MPN-Netzwerk E.V.	http://www.Mpn-netzwerk.de	Full
Germany	MPS Europe	http://mps-europe.org	Full
Germany	Multinational Interstitial Cystitis Association		Associate
Germany	Myelitis e.V.	http://www.myelitis.de	Full
Germany	NCL-Gruppe Deutschland e.V.	http://www.ncl-deutschland.de	Full
Germany	Nephie e.V. - Selbsthilfe nephrotisches Syndrom	http://www.nephie.de	Full
Germany	Netzwerk Hypophysen- und Nebennierenerkrankungen e.V. - Network pituitary and adrenal disorders	http://www.glandula-online.de	Full
Germany	OIFE - Osteogenesis Imperfecta Federation Europe	http://www.oife.org	Full
Germany	Patienten- und Selbsthilfeorganisation für Kinder und Erwachsene mit Kranker Speiseröhre Mit Kranker Speiseröhre	https://keks.org/	Full
Germany	Patientenverband Familiäre Amyloid Polyneuropathie	http://patientenverband-fap.de	Associate
Germany	PCH-Familie e.V.	https://pch-familie.de/	Full
Germany	Peutz-Jeghers-Germany e.V.	http://peutz-jeghers.eu	Full
Germany	PKD Familiäre Zystenniere e.V.	http://www.pkdcure.de	Full
Germany	Pro Retina Deutschland e.V.	http://www.pro-retina.de	Associate
Germany	Pulmonale Hypertonie e.V.	http://www.phev.de	Full
Germany	Sanfilippo Initiative e.V.	http://www.sanfilippoinitiative.org	Associate
Germany	Selbsthilfe EPP e.V.	http://www.epp-deutschland.de	Full
Germany	Selbsthilfe Ichthyose e.V.	http://www.ichthyose.de	Full

Germany	Selbsthilfegruppe Ektodermale Dysplasie e.V.	http://www.ektodermale-dysplasie.de	Full
Germany	Selbsthilfegruppe Für PXE-Erkrankte Deutschlands e.V.	http://www.pxe-shg.de	Full
Germany	Selbsthilfegruppe Glykogenose Deutschland e.V.	http://www.glykogenose.de	Full
Germany	Selbsthilfeorganisation für Menschen mit Anorektalfehlbildungen	http://www.soma-ev.de	Full
Germany	Sklerodermie Selbsthilfe e.V.	https://www.sklerodermie-sh.de/	Full
Germany	SMA Europe	http://www.sma-europe.eu	Full
Germany	SSADH-Defizit e.V.	http://ssadh.wordpress.com	Associate
Germany	Tom Wahlig Stiftung	http://www.hsp-info.de	Full
Germany	Verein Ahc18+	https://www.facebook.com/pages/Association-ahc18/606879759444135	Associate
Germany	Verein VHL (Von Hippel - Lindau) betroffener Familien e.V.	http://www.hippel-lindau.de	Full
Germany	XP – Freu(n)de Mondscheinkinder	http://www.xeroderm pigmentosum.de	Full
Germany	ZNM - Zusammen Stark! e. V.	http://www.znm-zusammenstark.org	Associate
Greece	"95" - Rare Alliance Greece	http://www.rarealliance.gr	Full
Greece	Angelman syndrome Greece	https://angelman.gr/	Full
Greece	Association of Greek Friends for Paediatric Immunology Primary Immunodeficiencies "Harmony"	http://www.paed-anosia.gr	Associate
Greece	Child's Heart	http://www.kardiapaidiou.gr	Full
Greece	Hellenic Cystic Fibrosis Association	http://www.cysticfibrosis.gr	Full
Greece	Hellenic Friedreich's Ataxia Association	https://www.hefaa.org	Full
Greece	Hellenic League against Rheumatism	http://www.arthritis.org.gr	Associate
Greece	Hellenic Myasthenia Gravis Association	http://www.myasthenia.gr	Full
Greece	Immune Deficiency Association GALINOS	https://galinossilogos.wixsite.com/galinos	Associate
Greece	Karkinaki Awareness for childhood and adolescent Cancer	http://www.karkinaki.gr	Associate
Greece	KRIKOS ZOIS Society for Patients and Friends of Patients with Inherited Metabolic Disease	http://www.krikoszois.gr	Full
Greece	Muscular Dystrophy Association Hellas	http://mdahellas.gr	Full
Greece	Panhellenic Association of Patients & Friends with Neurofibromatosis "Life With NF"		Associate
Greece	Panhellenic Association of Patients with Lysosomal Disorders	http://greeklysosomal.gr	Full
Greece	Parents and Friends of People with Rett Syndrome Association	http://www.rettgreece.gr	Associate
Greece	Pespa (Greek Alliance for Rare Diseases)	http://www.pespa.gr	Associate
Greece	Prader Willi Syndrome Association Hellas		Full
Greece	Pulmonary Hypertension of Greece – Hellenic Pulmonary Hypertension	http://www.hellenicpulmonaryhypertension.gr/	Associate
Greece	To Mellon- Association of People with Genetic Disorders	http://www.tomellon.com.gr	Full
Greece	Together for Life		Full

Greece	VHLFA Alliance in Greece	https://www.vhlgr.org/	Associate
Guatemala	Asociación Nacional Guatemalteca para las Enfermedades de depósito Lisosomal	http://angel-lisosomal.org/	Associate
Guatemala	Procrece	https://www.facebook.com/asociacionprocreceguatemala/	Associate
Hong Kong, SAR of China	Joshua Hellmann Foundation For Orphan Disease	http://www.jhforphandisease.org/	Associate
Hungary	Hungarian Haemophilia Society - Magyar Hemofília Egyesület	http://www.mhe.hu	Full
Hungary	Magyaórszági Mitochondriális Betegek Alapítványa	http://www.nbia.hu	Full
Hungary	Primer Immunhianyos Betegek Egyesülete	http://www.pibe.hu	Full
Hungary	Rare Diseases Hungary - HUFERDIS	http://www.rirosz.hu	Full
Iceland	AHC Federation of Europe	http://www.ahcfe.eu	Associate
Iceland	Alternating Hemiplegia of Childhood Association of Iceland	http://www.ahc.is	Full
Iceland	Einstok Born - Support Group for Children with Rare Disorders	http://www.einstokborn.is	Full
Iceland	Gudrun's Rett Syndrome Research Trust	http://rettenglar.yolasite.com	Associate
India	Indian Organization for Rare Diseases	https://www.rarediseases.in/	Associate
India	Organization For Rare Diseases India	https://ordindia.in/	Associate
Iran (Islamic Republic of)	Rare Disease Foundation of Iran	http://radoir.org/fa/	Associate
Ireland	22Q11 Ireland Support Group	http://www.22q11ireland.org	Full
Ireland	Alpha One Foundation	http://www.alpha1.ie	Full
Ireland	Barretstown Serious Fun	http://www.barretstown.org	Associate
Ireland	Cystic Fibrosis Ireland	http://www.cfireland.ie	Associate
Ireland	Cystinosis Ireland	http://cystinosis.ie	Full
Ireland	Debra Ireland	http://www.debraireland.org	Full
Ireland	European Sickle Cell Federation	https://escfederation.eu/	Associate
Ireland	Fighting Blindness	http://www.fightingblindness.ie	Full
Ireland	Friedreich's Ataxia Research Alliance	http://www.faraireland.ie	Full
Ireland	Irish Cancer Society	http://www.cancer.ie	Associate
Ireland	Neurofibromatosis Association of Ireland	http://www.nfaireland.ie	Full
Ireland	Popsycle Foundation	https://www.facebook.com/Popsycle01/	Associate
Ireland	Rare Diseases Ireland	http://rdi.ie/	Full
Ireland	Sickle Cell and Thalassaemie Ireland	http://www.sicklecellireland.ie	Full
Ireland	The Cavan Tommy Hoey Trust	https://www.facebook.com/the.cavan.tommy.hoey.trust/	Associate
Ireland	The Irish Fragile X Society	http://fragilexireland.org	Full
Ireland	The Irish Society for Mucopolysaccharide and Related Diseases	http://www.mpssociety.ie/wordpress/	Full
Ireland	The Ultra Rare Diseases, Disorders & Disabilities Foundation	http://www.ultrarare-disease.uk	Associate
Ireland	Vasculitis Ireland Awareness	http://www.vasculitis-ia.org	Full

Israel	CdLS Israeli Foundation	https://www.cdlsisrael.org.il/	Associate
Israel	GRIN Disorders Research Foundation	http://www.gringn.com/	Associate
Israel	Israel Adult Polyglucosan Body Disease		Associate
Israel	Little Steps Association	https://www.littlesteps.org.il/	Associate
Italy	ABC Associazione Bambini Cri Du Chat	http://www.criduchat.it	Full
Italy	ACMT- Rete per la malattia di Charcot-Marie-Tooth OdV	http://www.acmt-rete.it	Full
Italy	Acondroplasia - Insieme Per Crescere - Onlus	http://www.acondroplasiaonlus.com	Full
Italy	AIBWS ODV	http://www.aibws.org	Full
Italy	Amici Della Porfiria - San Pio Da Pietrelcina Onlus	http://www.porfiria.it	Associate
Italy	Angeli Noonan	http://www.angelinoonan.it	Full
Italy	Aniridia Italiana APS	http://www.aniridia.it/	Full
Italy	Assi Gulliver - Associazione Sindrome di Sotos Italia	https://www.assigulliver.it/	Full
Italy	Associazone Nazionale Pemfigo/Pemfigoide	https://www.pemfigo.org/	Full
Italy	Associazione conto alla Rovescia	http://www.acar2006.org	Full
Italy	Associazione Famiglie di Soggetti con Deficit dell'Ormone della Crescita ed altre Patologie	http://www.afadoc.it	Full
Italy	Associazione Fondazione Italiana HHT "Onilde Carini"	http://www.hht.it/	Full
Italy	Associazione Italiana Adrenoleucodistrofia Onlus	https://www.adrenoleucodistrofia.it/	Associate
Italy	Associazione Italiana Cistite Interstiziale	http://www.aici-onlus.it	Full
Italy	Associazione Italiana Dei Cardiopatici Congeniti Adulti - Italian Guch Association	http://www.aicca.eu	Associate
Italy	Associazione Italiana Estrofia Vescicale-Epispadia ODV	http://www.estrofiavescicale.it	Full
Italy	Associazione Italiana Gaucher Onlus	http://www.gaucheritalia.org	Full
Italy	Associazione Italiana Glicogenosi	http://www.aig-aig.it	Full
Italy	Associazione Italiana Laryngectomizzati	http://www.ailar.it	Associate
Italy	Associazione Italiana Leucodistrofie Unite	http://digilander.libero.it/ailu/	Full
Italy	Associazione Italiana Linfoistiocitosi Emofagocitica	https://www.aileonlus.org/	Associate
Italy	Associazione Italiana Malati di Alcaptonuria	http://www.aimaku.it	Full
Italy	Associazione Italiana Malformazione di Arnold-Chiari Child	https://www.aima-child.it/	Full
Italy	Associazione Italiana Miastenia e Malattie Immunodegenerative - Amici del Besta Onlus	http://www.miastenia.it	Full
Italy	Associazione Italiana Miastenia Onlus	http://www.viverelamiastenia.it	Full
Italy	Associazione Italiana Morbo di Hirschsprung	http://amorhi.org	Associate
Italy	Associazione Italiana Mucopolisaccaridosi e Malattie Affini	http://www.aimps.it	Full
Italy	Associazione Italiana Niemann Pick Onlus	http://www.niemannpick.org	Full
Italy	Associazione Italiana per la lotta alle PHTS	http://www.ptenitalia.org	Full
Italy	Associazione Italiana per le Malformazioni Anorettali	http://www.aimar.eu	Full
Italy	Associazione Italiana Rene Policistico Onlus	https://www.renepolicistico.it/	Full

Italy	Associazione Italiana Sindrome di Ehlers-Danlos	https://www.aised.it/	Full
Italy	Associazione Italiana Sindrome di Poland ODV	http://www.sindromedipoland.org	Full
Italy	Associazione Italiana Sindrome e malattia di Behçet	http://www.behcet.it	Full
Italy	Associazione Italiana Sindrome X Fragile	http://www.xfragile.net	Full
Italy	Associazione Italiana Siringomielia e Arnold Chiari	http://www.aismac.org	Full
Italy	Associazione Italiana Sostegno Malattie Metaboliche Ereditarie Onlus	http://www.aismme.org	Full
Italy	Associazione LAM Italia Onlus	http://www.lam-italia.org	Full
Italy	Associazione Ligure Talassemici Onlus	http://www.althonlus.org	Full
Italy	Associazione Malati Di Hailey Hailey Disease		Full
Italy	Associazione Malattie Rare Dell'Alta Murgia Onlus	http://www.amaram.it	Associate
Italy	Associazione Nazionale Angioma Cavernoso Cerebrale	https://www.anaccaps.org/	Full
Italy	Associazione Nazionale Persone con Malattie Reumatiche	http://www.apmar.it	Full
Italy	Associazione p63 Sindrome E.E.C. International APS	http://www.sindrome-eec.it	Associate
Italy	Associazione per le Immunodeficienze Primitive ODV	http://www.aip-it.org	Full
Italy	Associazione Per L'Informazione e lo Studio della Acondroplasia	http://www.aisac.it	Full
Italy	Associazione Persone Williams Italia Onlus	http://www.apwitalia.org	Full
Italy	Associazione Poic e dintorni Onlus	https://www.poic-e-dintorni.org/	Full
Italy	Associazione S.P.R.IN.T.	https://www.associazionesprint.org/	Associate
Italy	Associazione Sclerosi Tuberosa	http://www.sclerosituberosa.org	Full
Italy	Associazione Sindrome di Alström / Italian Association for Alstrom Syndrome	https://www.alstrom.it/	Full
Italy	Associazione Sindrome Nefrosica Italia	http://www.asnit.org	Full
Italy	Associazione Spina Bifida Italia	https://www.spinabifidaitalia.it/	Full
Italy	Associazione Studio Malattie Metaboliche Ereditarie Onlus	http://www.cometaasmme.org	Full
Italy	Associazione Veneta per la Lotta alla Talassemia	http://www.avlt.it	Full
Italy	CIDP Italia Onlus	http://www.cidp.it	Full
Italy	Collagene Vi Italia Onlus - Col6	http://www.col6.it	Full
Italy	Costello.Cfc - Associazione Italiana Sindrome Di Costello - Cardiofaciocutanea - Rasopatie - Onlus	http://www.sindromedicostello.it	Full
Italy	Debra Italia Onlus	http://www.debraitalia.com/	Full
Italy	Dravet Italia Onlus	http://www.dravet-italia.org	Full
Italy	European Congenital Heart Disease Organisation	http://echdo.eu	Associate
Italy	Federazione Sindrome di Prader Willi Italia	http://www.praderwilli.it	Full
Italy	Fondazione Alessandra Bisceglia ViVa Ale Onlus	http://www.fondazionevivaale.org	Associate
Italy	Fondazione Lega Italiana Ricerca Huntington	https://lirh.it/en	Full
Italy	FOP Italia Onlus	http://www.fopitalia.it	Full

Italy	Gli Amici di Daniela	http://www.amicididaniela.it	Associate
Italy	Gli Equilibristi HIBM	http://www.gliequilibristi-hibm.org/	Full
Italy	Gruppo "Italia - Glioblastoma Multiforme - Cancro al Cervello"	https://www.facebook.com/groups/italia.glioblastoma.multiforme/	Associate
Italy	Gruppo Famiglie Dravet Associazione Onlus	http://www.sindromedidravet.org/	Full
Italy	Gruppo Familiari Beta-Sarcoglicanopatie	http://www.beta-sarcoglicanopathy.org/	Full
Italy	Gruppo Italiano per la lotta alla Sclerodermia Onlus	http://www.sclerodermia.net	Full
Italy	HHT Europe	http://www.hhteurope.org	Full
Italy	HHT Onlus	http://www.hhtonlus.com	Full
Italy	Incontinentia Pigmenti Associazione Italiana Onlus	http://www.incontinentiapigmenti.it	Associate
Italy	La Strada per l'Arcobaleno	http://www.stradaperlarcobaleno.com	Full
Italy	Linfa Odv	http://www.associazionelinfa.it/	Full
Italy	LND Famiglie Italiane odv	http://www.lesch-nyhan.eu	Full
Italy	Mitocon- Insieme per lo Studio e la Cura delle Malattie Mitochondriali - Onlus	http://www.mitocon.it	Associate
Italy	PANDAS Italia	http://www.pandasitalia.com	Full
Italy	Parent Project aps	http://www.parentproject.it	Full
Italy	PKS Kids Italia Onlus	http://www.pksitalia.org	Full
Italy	Retina Italia Onlus	http://www.retinaitalia.org/	Full
Italy	Ring 14 International	http://www.ring14.org	Full
Italy	SOD Italia - Associazione Septo Optic Dysplasia and Other Neuroendocrine Disorders	http://www.soditalia.it	Full
Italy	Un Filo per la Vita ANAD IICB	http://www.unfiloperlavita.it	Full
Italy	UNIAMO- Rare Diseases Italy	http://www.uniarno.org	Full
Italy	Unione Italiana Ittiosi	http://www.ittiosi.it	Full
Italy	Unione Italiana Lotta Alla Distrofia Muscolare	http://www.uildm.org/	Full
Italy	Unione Trapiantati Polmone - Padova ODV	https://oltrelamalattia.it/	Full
Italy	United Onlus	http://www.unitedonlus.org	Full
Italy	World Federation of Incontinence Patients	http://www.wfip.org	Associate
Italy	XLPRD International Association	http://www.xlpdr.com	Associate
Japan	Japan Patient Association	http://www.nanbyo.jp	Associate
Kazakhstan	Association of Support to Patients with Orphan Diseases in the Republic of Kazakhstan		Associate
Kazakhstan	Patients with Cancer and Rare Diseases Support Association		Associate
Kosovo	Rare Diseases Kosovo (Shoqata e Semundje te Rralla Kosove)	https://www.facebook.com/Shoqata-e-S%C3%ABmundjeve-t%C3%AB-Rralla-Kosov%C3%AB-2034022230042375/	Associate
Latvia	Association of People with Special Needs "Motus Vita"	http://www.motusvita.lv/index.php?lang=en	Associate

Latvia	Latvian Alliance for Rare Diseases	http://www.retasslimibas.lv	Full
Latvia	Rare Disease Association "Caladrius"	http://www.inbox.lv	Associate
Lebanon	Lebanese Association for Neuromuscular Diseases	http://landforhope.org	Associate
Lithuania	Community Of Oncohematological Patient Organisations Kraujas	http://www.kraujas.lt	Full
Lithuania	Rare Diseases Lithuania (Vaikų retų ligų asociacija)	http://retosligos.lt/	Associate
Luxembourg	Alan - Maladies Rares Luxembourg	http://www.alan.lu	Full
Luxembourg	EDS Lëtzebuerg a.s.b.l.	https://edsletzebuerg.lu/2/	Associate
Luxembourg	Een Häerz Fir Kriibskrank Kanner Asbl	http://www.kriibskrankkanner.lu	Full
Luxembourg	Fondatioun Kriibskrank Kanner	http://www.fondatioun.lu	Associate
Luxembourg	Rett Syndrome Europe	http://www.rettsyndrome.eu	Full
Luxembourg	Syndrome de Matfan den-i.lu asbl	http://www.den-i.lu/	Associate
Malaysia	Malaysia Metabolic Society	http://www.mms.my	Associate
Malaysia	Malaysian Rare Disorders Society	http://www.mrds.org.my	Associate
Malta	National Alliance For Rare Diseases Support - Malta	http://www.rarediseasesmalta.com	Full
Mexico	Asociacion de Gaucher de Mexico		Associate
Mexico	Proyecto Pide Un Deseo Mexico lap	http://www.pideundeseo.org	Associate
Mexico	Red Sanfilippo	http://www.redsanfilippo.org	Associate
Montenegro	National Organisation for Rare Diseases	http://www.rijetkebolesti.com	Associate
Morocco	Association Marocaine de la Fièvre Méditerranéenne Familiale et des autres Fièvres Récurrentes		Associate
Morocco	Sun'Hop		Associate
Nepal	GBS/CIDP Foundation Nepal		Associate
Netherlands	ALS Patients Connected	http://www.alspatientsconnected.com	Full
Netherlands	Amyloidose Nederland	http://amyloidose.nl	Full
Netherlands	Ataxie Vereniging Nederland	http://www.ataxie.nl	Full
Netherlands	Bijniervereniging (Dutch Adrenal Patient Society)	http://www.nvacp.nl	Full
Netherlands	Childhood Cancer International -Europe	https://ccieurope.eu/	Full
Netherlands	CMTC-OVM	http://www.cmtc.nl	Full
Netherlands	Cornelia de Lange Syndrome World Federation	http://www.cdlsworld.org	Full
Netherlands	European Cleft Organisation	http://europeancleft.org/	Associate
Netherlands	European Sarcoidosis Foundation	https://www.sarcoidosis.eu/w/en/	Associate
Netherlands	European Society For Phenylketonuria	http://www.espku.org	Associate
Netherlands	European VHL (Von Hippel-Lindau) Federation	http://www.vhl-europa.org	Associate
Netherlands	Fabry Support & Informatie Groep Nederland	http://www.fabry.nl	Full
Netherlands	Fibrodysplasia Ossificans Progressiva Stichting Nederland	http://www.fopstichting.nl	Full
Netherlands	International Mito Patients	http://www.mitopatients.org	Full
Netherlands	International Painful Bladder Foundation	http://www.painful-bladder.org	Associate

Netherlands	International Porphyria Patient Network	https://porphyria.network/IPPN/	Associate
Netherlands	Interstitiële Cystitis Patientenvereniging	http://www.icpatienten.nl	Full
Netherlands	ITP Patientenvereniging	http://www.itp-pv.nl	Full
Netherlands	KAISZ - Children with a Autoimmuum or Autoinflammatory Disease	http://www.kaisz.nl	Full
Netherlands	MSS (Marshall-Smith Syndrome) Research Foundation	http://www.marshallsmith.org	Full
Netherlands	National Association ReumaZorg Nederland	https://reumazorgnederland.nl/	Associate
Netherlands	Nationale Vereniging L.E. patiënten	http://www.nvle.org/	Full
Netherlands	Nederlands Netwerk voor Lymfoedeem en Lipoedeem	http://www.lymfoedeem.nl	Associate
Netherlands	Nederlandse Hypofyse Stichting (Dutch Pituitary Foundation)	http://www.hypofyse.nl	Full
Netherlands	Nederlandse Leverpatienten Vereniging	http://www.leverpatientenvereniging.nl	Full
Netherlands	Nederlandse Phenylketonurie Vereniging / Dutch Pku Association	http://Www.pkuvereniging.nl	Full
Netherlands	Nederlandse Vereniging van Hemofilie-Patiënten/Netherlands Haemophilia Society	http://www.nvhp.nl	Full
Netherlands	Nephceurope	http://nephceurope.eu/nc/	Associate
Netherlands	Neurofibromatose Vereniging Nederland	http://www.neurofibromatose.nl	Full
Netherlands	Nevus Netwerk Nederland	https://nevusnetwerk.nl/	Full
Netherlands	Oscar Nederland	http://www.oscarnederland.nl	Full
Netherlands	Patientenorganisatie Fibreuze Dysplasie	http://www.fibreuzedysplasie.eu	Full
Netherlands	Patiëntenvereniging voor Blaasextrophie Nederland	https://www.blaasextrophy.nl	Full
Netherlands	Sarcoidose.NI	http://www.sarcoidose.nl	Full
Netherlands	Spierziekten Nederland - Dutch Association for Neuromuscular Disease	http://www.vsn.nl	Full
Netherlands	Stichting AA & PNH Contactgroep	http://www.aaenph.nl	Full
Netherlands	Stichting Christianson Syndrome Europe	https://cs-europe.org/	Associate
Netherlands	Stichting Hart4Onderzoek / Heart4Research	https://hart4onderzoek.nl/	Full
Netherlands	Stichting Histiocytose Nederland	http://www.histio.nl	Full
Netherlands	Stichting IJzersterk	http://www.stichtingijzersterk.nl	Associate
Netherlands	Stichting Kans voor PKAN Kinderen	https://kansvoorpkankinderen.nl	Full
Netherlands	Stichting Net-Groep	http://www.net-kanker.nl	Full
Netherlands	Stichting Overdruksyndroom NL	https://sosnl.nl	Full
Netherlands	Stichting Pierre Robin Europe - Pierre Robin Europe Foundation	http://pierreroberineurope.com	Full
Netherlands	Stichting RPF Nederland / Dutch RPF Foundation	https://rpf.nl/	Full
Netherlands	Stichting Shwachman Diamond Syndrome Support Holland	http://www.shwachman.nl	Full
Netherlands	Stichting Spierkracht	http://www.stichtingspierkracht.com/	Associate
Netherlands	Stichting Stofwisselkracht	http://www.stofwisselkracht.nl	Full
Netherlands	Stichting TAPS Support/ TAPS Support Foundation	https://www.stichtingtapssupport.com/	Associate

Netherlands	Stichting Terre - Rett Syndrome Foundation	http://www.stichtingterre.nl	Full
Netherlands	Stichting voor Afweerstoornissen	http://www.stichtingvoorafweerstoornissen.nl	Full
Netherlands	Stichting Zeldzame Bloedziekten	http://www.bloedziekten.nl	Associate
Netherlands	Thyroid Cancer Alliance	http://www.thyroidcanceralliance.org	Full
Netherlands	Vasculitis Stichting	http://www.vasculitis.nl	Full
Netherlands	Vereniging van Ehlers Danlos Patienten	http://www.ehlers-danlos.nl/	Full
Netherlands	Vereniging voor Ichthyosis Netwerken	https://ichthyosisnetwerken.nl/	Full
Netherlands	Volwassenen, Kinderen En Stofwisselingsziekten	http://www.stofwisselingsziekten.nl	Full
Netherlands	VSOP - Vereniging Samenwerkende Ouder En Patiëntenorganisaties	http://www.vsop.nl	Full
Netherlands	World Alliance of Pituitary Organizations	http://www.wapo.org	Associate
Netherlands	World Duchenne Organization	http://worldduchenne.org	Full
New Zealand	Rare Disorders NZ	http://www.nzord.org.nz	Associate
North Macedonia	Association for help and support of patients and their caregivers with Haematological Diseases	http://www.hema.org.mk	Associate
North Macedonia	Association for persons with Spinal Muscular Atrophy- Stop SMA	https://www.facebook.com/STOP-SMA-Macedonia-%D0%A1%D0%A2%D0%9E%D0%9F-%D0%A1%D0%9C%D0%90-1916753535041997/	Associate
North Macedonia	Life With Challenges	http://challenges.mk/?p=2288&lang=en	Full
North Macedonia	National Alliance For Rare Diseases of North Macedonia		Full
North Macedonia	Save Liver Association of Patients with Liver Diseases	https://www.facebook.com/udrugaslap/	Full
Norway	Aniridia Europe	http://www.aniridia.eu	Full
Norway	European Huntington Association	http://eurohuntington.org/	Full
Norway	Frambu - Resource Centre For Rare Disorders	http://www.frambu.no	Full
Norway	Hjernesvulstforeningen (Norwegian Brain Tumour Association)	https://hjernesvulst.no/	Full
Norway	Hypopara Norge	http://www.hypopara.no	Full
Norway	Morbus Addison Association Norway	http://www.addison.no	Full
Norway	MPS-Foreningen I Norge	http://mpsforeningen.no	Associate
Norway	Norsk Forening For Arvelig Spastisk Paraparese / Ataksi	http://www.naspa.no	Full
Norway	Norsk Forening For Ehlers-Danlos Syndrom	http://www.eds-foreningen.no	Full
Norway	Norsk Forening for Osteogenesis Imperfecta/The Norwegian Osteogenesis Imperfecta Association	http://www.nfoi.no	Full
Norway	Norsk Forening For Tuberos Sklerose	http://www.nfts.no	Full
Norway	Norwegian Federation of Organisations of Disabled People (Funksjonshemmedes Fellesorganisasjon)	https://www.ffe.no/	Full

Norway	Norwegian organisation for Prader Willis syndrome	https://www.prader-willis.no/	Full
Norway	Oslerforeningen Norge	http://www.osler.no	Full
Poland	Debra Polska	http://www.debra-kd.pl	Full
Poland	Foundation of Borys the Hero /Fundacja Bohatera Borysa	http://bohaterborys.pl/	Associate
Poland	Fundacja SMA (SMA Foundation Poland)	http://www.fsma.pl	Full
Poland	Fundacja Umiec Pomagac (Foundation For RD MPS)	http://www.umiecpomagac.org	Full
Poland	Matio Fundacji Pomocy Rodzinom I Chorym Na Mukowiscydozę/MATIO Polish CF Foundation	http://www.mukowiscydoza.pl	Full
Poland	Polish National Forum on the treatment of Orphan Diseases - Orphan	http://www.rzadkiechoroby.pl	Full
Poland	Polish PKU and RD Association "Ars Vivendi"	http://www.fenyloketonuria.org	Full
Poland	Polish Society of MPS and Related Diseases	http://www.mps-society.pl	Full
Poland	Polskie Stowarzyszenie Na Rzecz Osób Z AHC	http://www.stow.ahc-pl.org/	Associate
Poland	Rett Syndrome Poland - Ogólnopolskie Stowarzyszenie Pomocy Osobom Z Zespołem Retta	http://www.rettsyndrome.pl	Full
Poland	The Dina Radziwillowa Child's Heart Foundation	http://www.sercedziecka.org.pl	Full
Portugal	andLINFA Associação Nacional de Doentes Linfáticos / National Association of Sufferers of Lymphatic Disorders	http://andlinfa.pt/In%C3%ADcio.php	Full
Portugal	Associação Nacional De Displasias Ósseas	http://www.andoportugal.org	Associate
Portugal	Associação Nacional para Divulgar e Orientar para Combater e Enfrentar a Tay Sachs e outras Gangliosidoses	http://doce.pt/wp/	Associate
Portugal	Associação Portuguesa CDG e Outras Doencas Metabolicas	http://www.apcdg.com	Associate
Portugal	Associação Portuguesa De Charcot-Marie-Tooth	https://www.facebook.com/associacao.portuguesa.charcot.marie.tooth/	Full
Portugal	Associação Portuguesa De Insuficientes Renais	http://www.apir.org.pt	Full
Portugal	Associação Portuguesa de Leucemias e Linfomas	http://www.apll.org	Full
Portugal	Associação Portuguesa De Neuromusculares	http://www.apn.pt	Full
Portugal	Associação Portuguesa de Osteogénese Imperfeita	http://www.apoi.pt	Full
Portugal	Associação Sanfilippo Portugal	http://www.sanfilippoportugal.com	Full
Portugal	EVITA	http://www.evita cancro.org/	Associate
Portugal	Fedra - Federação Portuguesa De Doenças Raras	http://www.fedra.pt	Associate
Portugal	Liga Portuguesa contra as Doenças Reumáticas	http://www.lpcdr.org.pt	Full
Portugal	Rarissimas - Associação Nacional De Deficiencias Mentais E Raras	https://rarissimas.pt/	Full
Portugal	RD-Portugal - União de Associações das Doenças Raras de Portugal	https://raras.pt/	Associate
Republic of Moldova	Copiii Ploii	https://www.facebook.com/AO-Copiii-Ploii-686485228086936/	Full

Romania	Asociatia Copiilor Cu Boli Mitocondriale/Association of Children with Mitochondrial Diseases	https://cure-echs1.com/	Associate
Romania	Asociatia Copilul Meu-Inima Mea	http://www.acmim.ro	Full
Romania	Asociatia Nationala Miastenia Gravis Romania /Romanian Myasthenia Gravis Association	http://www.miastenie.ro	Full
Romania	Asociatia Persoanelor Cu Glicogenoza (APG Romania)	https://glicogenoza.ro/	Associate
Romania	Asociatia Persoanelor Cu Talasemie Majora	http://www.talasemia.ro	Full
Romania	Asociatia Română De Cancere Rar	http://www.arcrareromania.ro	Associate
Romania	Asociatia Romana pentru Boala Neurologice Periferice/Romanian Association of Perypheral Neurological Diseases	https://arbnp-cidp.ro/	Full
Romania	Asociatia Smacare	http://www.amiotrofie-spinala.ro	Full
Romania	Asociatia Werdnig Hoffman Awh	https://www.facebook.com/werdnighoffman/	Full
Romania	Autoimmune Diseases Patients Association	http://www.apaa.ro	Associate
Romania	Charcot Marie Tooth Romania Association	http://www.asociatiacmt.ro	Associate
Romania	DMD Care	https://dmdcare.org	Full
Romania	Mastocytosis Support Association Romania	http://www.mastocitoza.ro	Associate
Romania	Neuro Move CMT Association	https://neuromovecmt.ro/	Associate
Romania	Romanian National Alliance For Rare Diseases	http://bolirareromania.ro	Full
Romania	Romanian Prader Willi Association	http://www.apwromania.ro	Full
Russian Federation	Help to Cystic Fibrosis Patients		Full
Russian Federation	Interregional Public Organisation For Gaucher Disease	http://www.gaucher.ru	Full
Russian Federation	Interregional Public Organisation Of Patients With Fabry Disease "The Road To Life"	http://www.fabryufa.ru	Full
Russian Federation	Inter-Regional Support Centre dor Patients with Aniridia " Iris"	http://www.aniridia.ru	Associate
Russian Federation	Look to see	http://looktosee.ru	Full
Russian Federation	MPS Russia	http://www.mps-russia.org	Full
Russian Federation	National Association of Organization of Patient with Rare Diseases "Genetics"	http://www.nacgenetic.ru/	Associate
Russian Federation	NGO "Fragile Children"	http://www.osteogenez.ru	Full
Russian Federation	Russian Association of Rare Diseases	http://www.rare-diseases.ru	Full
Russian Federation	Russian Patient Association	http://www.patients.ru/en	Associate
Russian Federation	Russian Rett Syndrome Asociation	http://www.rettsyndrome.ru	Associate
Russian Federation	SPIPORZ Union of patients with rare diseases and rare disease patients organsiations	http://www.spiporz.ru	Associate
Russian Federation	The Association of Primary Immunodeficiency Patients	http://www.oppid.ru	Full
Serbia	Child Rare Disease Support and Research Association Life	http://www.zivotorg.org	Associate
Serbia	Childhood Cancer Parent Organisation "Zvoncica"	http://www.zvoncica.org.rs/	Full

Serbia	Citizens Association "Bromologos"	https://fenilketonurija.com/	Associate
Serbia	DMD Serbia	http://dmdsrbija.rs/	Full
Serbia	Lymphoma Patients' Association	http://www.lipa.org.rs	Associate
Serbia	National Organization For Rare Diseases of Serbia	http://www.norbs.rs	Full
Singapore	Rare Disorders Society (Singapore)	http://www.rdss.org.sg	Associate
Slovakia	Debra SR	http://www.debra-slovakia.org	Full
Slovakia	European Polio Union	http://www.europeanpolio.eu	Full
Slovakia	Organisation of Muscular Dystrophy in the Slovak Republic/Organizácia muskulárnych dystrofií v SR	http://www.omdvsr.sk	Full
Slovakia	Slovak Alliance of Rare Diseases	http://www.sazch.sk	Full
Slovakia	Slovak Cystic Fibrosis Association	http://www.cfasociacia.sk	Full
Slovakia	Zdruzenie Ojedlinelych Genetických Ochorení	http://www.zogo.sk/	Associate
Slovenia	Association of Patients with Blood Diseases - Društvo Bolnikov S Krvnimi Boleznimi	http://www.drustvo-bkb.si	Full
Slovenia	Debra Slovenia - Društvo Debra Slovenija	http://www.debra-slovenia.si	Full
Slovenia	EAMDA - European Alliance of Neuromuscular Disorders Associations	http://www.eamda.eu	Full
Slovenia	European Foundation for SATB2-Associated Syndrome (SATB2 Europe)	https://www.satb2europe.org/	Associate
Slovenia	Fabry Patients Association Slovenia / Društvo Bolnikov S Fabryjevo Boleznijo Slovenije	http://www.sb-sg.si	Full
Slovenia	Foundation of Child Neurology	http://peunetro.peukr.si/english/foundation/	Associate
Slovenia	Viljem Julijan Association for Children with Rare Diseases	http://viljem-julijan.si/	Full
Slovenia	Zavod Bernardi Ventrella	https://www.zavodbv.org/	Associate
South Africa	Primary Immunodeficiency Network of South Africa	http://www.pinsa.org.za	Associate
South Africa	Rare Diseases South Africa NPC	http://www.rarediseases.co.za	Associate
Spain	Acción y Cura Para Tay-Sachs	http://www.actays.org	Full
Spain	AHUCE - Asociación nacional Huesos de Cristal OI España	http://www.ahuce.org	Full
Spain	Alianza Española de Familias de von Hippel Lindau	http://www.alianzavhl.org	Full
Spain	Asociació Catalana de las Neurofibromatosis	http://www.acnefi.com/castella/gamhome.htm	Full
Spain	Asociacion Albi España	http://www.asociacionalbi.com/	Full
Spain	Asociacion Andaluza de Fibrosis Quística	http://fqandalucia.org/	Full
Spain	Asociación Andaluza de pacientes con Síndrome de Tourette y Trastornos Asociados	http://www.tourette.es	Full
Spain	Asociación Artrogriposis Múltiple Congénita	https://artrogriposis.org/	Full
Spain	Asociación Chiari y Siringomielia del Principado de Asturias	http://www.chyspa.org	Full
Spain	Asociación Ciudadana de Afectados de Cistitis Intersticial	http://www.acaci.es/	Full

Spain	Asociación de Afectados de Neurofibromatosis	http://www.neurofibromatosis.es	Full
Spain	Asociación de Afectados por Displasia Ectodérmica	http://www.displasiaectodermica.org	Full
Spain	Asociación de Afectados por Hiperinsulinismo Congénito	http://hiperinsulinismocongenito.org/	Full
Spain	Asociación de Atrofia de Nervio Optico de Leber	http://www.asanol.com	Full
Spain	Asociación De Enfermedades Raras D'genes	http://www.dgenes.es/	Full
Spain	Asociación de Epidermólisis Buloosa de España (Debra Spain)	http://www.debra.es	Full
Spain	Asociación de Esclerodermia Castellon	http://www.esclerodermia.es	Full
Spain	Asociación de Familiares y Afectados por Lipodistrofias	http://www.aelip.org	Full
Spain	Asociación De Hemoglobinuria Paroxística Nocturna	http://www.hpne.org	Associate
Spain	Asociación De Nevus Gigante Congénito	http://asonevus.org/	Full
Spain	Asociación de pacientes ASMD España	https://www.asmd.es/	Associate
Spain	Asociación de Pacientes de Uveítis	https://www.asociacionauvea.es/	Full
Spain	Asociación Enfermedad de Kawasaki	https://asenkawa.org/	Full
Spain	Asociación Española Aniridia	http://www.aniridia.es	Full
Spain	Asociación Española de Afectados por Sarcoma	http://www.aesarcomas.org	Full
Spain	Asociación Española de Amiloidosis	http://www.amilo.es/	Associate
Spain	Asociación Española de Angioedema Familiar	http://www.angioedema-aedaf.org	Full
Spain	Asociación Española de Enfermos de Glucogenosis	http://www.glucogenosis.org	Full
Spain	Asociación Española De Enfermos De Pompe	http://www.asociaciondepompe.org	Associate
Spain	Asociación Española de Enfermos y Familiares de la Enfermedad De Gaucher España	http://www.aeefegaucher.es	Full
Spain	Asociación Española de Esclerodermia	https://esclerodermia.com	Full
Spain	Asociación Española de Familiares y Enfermos de Wilson	http://www.enfermedaddewilson.org	Full
Spain	Asociación Española de Fibrodisplasia Osificante Progresiva	http://www.aefop-es.org	Full
Spain	Asociación Española De Fiebre Mediterranea Familiar	http://fmf.org.es	Full
Spain	Asociación Española de Ictiosis	http://www.ictiosis.org	Full
Spain	Asociación Española de Mastocitosis y Enfermedades Relacionadas	http://www.mastocitosis.com	Full
Spain	Asociación Española de Pacs1	http://pacs1.es/	Associate
Spain	Asociación Española De Paraparesia Espástica Familiar Strümpell-Lorrain	http://www.aepf.org	Full
Spain	Asociación Española de Porfiria	http://www.porfiria.org	Full
Spain	Asociación Española De Raquitismos y Osteomalacia Heredados	https://aeryoh.org/	Associate
Spain	Asociación Española de Síndrome De Poland	http://www.aesip.es	Full
Spain	Asociación Espanola deficit de Lipasa Acida Lisosomal	http://www.aelald.org	Full
Spain	Asociación Española del síndrome CDG	http://aescdg.com/	Associate
Spain	Asociación Española del Síndrome de Joubert		Full

Spain	Asociación Española del Síndrome de Schaaf-Yang	https://www.aesys.org/	Full
Spain	Asociación Española Síndrome de Sjögren	http://www.aesjogren.org	Full
Spain	Asociación HHT España	http://www.asociacionhht.org	Full
Spain	Asociación Madrileña de Pacientes con Síndrome de Gille de la Tourette y Trastornos Asociados	https://www.ampastta.com/	Full
Spain	Asociación Nacional Amigos De Arnold Chiari	http://www.arnoldchiari.es/	Full
Spain	Asociación Nacional de Dermatomiositis Juvenil	https://anadeju.org/	Full
Spain	Asociación Nacional de Hipertensión Pulmonar	http://www.hipertensionpulmonar.es	Full
Spain	Asociación Nacional Síndrome de Apert y otras Craneosinostosis Sindrómicas	http://www.ansapert.org	Full
Spain	Asociación Retina Murcia	https://www.retumur.org/	Full
Spain	Asociación Síndrome de Angelman	http://www.angelman-asa.org	Full
Spain	Asociación Síndrome de Lowe de España	http://www.sindromelowe.es	Full
Spain	Asociación Síndrome Lesch Nyhan España	https://www.facebook.com/asociacion.sindromeleschnyhanespana	Full
Spain	Asociación Stop Sanfilippo	http://www.stopsanfilippo.org	Associate
Spain	Asociación Xeroderma Pigmentosum	https://xerodermapigmentosum.es/	Full
Spain	Associació Catalana de la Delecció 22Q	http://www.22q.cat	Full
Spain	Associació d'Apràxia Ocular i Malalties Associades	http://apraxiaocular.blogspot.com	Associate
Spain	Associación Catalana De Enfermedades Neuromusculares	http://www.asecatalunya.com	Full
Spain	De Neu - Asociación De Enfermedades De Los Neurotransmisores	http://www.deneu.org	Full
Spain	Duchenne Parent Project España	http://www.duchenne-spain.org	Full
Spain	European Network For Rare And Congenital Anaemias	http://www.enerca.org	Associate
Spain	FEDER - Federación Española De Enfermedades Raras	http://www.enfermedades-raras.org	Full
Spain	Federació Catalana de Malalties Minoritàries	https://www.fecamm.org/portal1/m_index.asp?idioma=1	Full
Spain	Federación de Asociaciones de Retinosis Pigmentaria de España	http://www.retinosifarpe.org	Full
Spain	Federación de Ataxias de España	http://www.fedaes.org	Full
Spain	Federación Española de Enfermedades Neuromusculares	http://www.asec-esp.org	Full
Spain	Federación Española De Fibrosis Quística	http://www.fibrosis.org/	Full
Spain	Federación Española De Hemofilia	http://www.hemofilia.com	Full
Spain	Federación Española de Padres con Niños con Cáncer	http://www.cancerinfantil.org	Full
Spain	Federación Española del Síndrome X Frágil	http://www.xfragil.org	Full
Spain	Fundació Catalana d'ELA Miquel Valls (Miquel Valls Foundation)	http://www.elacat.org	Associate
Spain	Fundación ALPE Acondroplasia	https://www.fundacionalpe.org	Full

Spain	Fundación Andrés Marcio, Niños Contra La Laminopatía	http://www.fundacionandresmarcio.org	Full
Spain	Fundacion Libellas	https://fundacionlibellas.org	Associate
Spain	Fundación Mari Paz Jiménez Casado	https://www.fundacionmaripazjimenez.org	Full
Spain	Fundación Niemann-Pick de España	http://www.fnp.es	Full
Spain	Fundación Síndrome 5P Menos	http://www.fundacionsindrome5p.org	Full
Spain	Fundación Síndrome de Dravet - Dravet Syndrome Foundation	http://www.dravetfoundation.eu	Full
Spain	Fundacion Sindrome De West	http://www.sindromedewest.org	Full
Spain	Fundación Síndrome Wolf Hirschhorn 4P-	http://www.4pmenos.org	Full
Spain	Hipertension Pulmonar España Organizacion De Pacientes	http://www.hipertension-pulmonar.com	Associate
Spain	Instituto de Investigación y Desarrollo Social de Enfermedades Poco Frecuentes	http://www.pocofrecuentes.org	Associate
Spain	Lymphoma Coalition	http://www.lymphomacoalition.org/	Associate
Spain	MPS Lisosomales	http://www.mpsesp.org/	Full
Spain	Pequeños Superheroes	https://pequenossuperheroes.org/	Associate
Spain	SAF España	https://www.antifosfolipido.es/	Full
Spain	SAMS - Síndromes Arrítmicos Relacionados con la Muerte Súbita	http://samsasociacion.com/	Full
Spain	Sense Barreres de Petrer	https://sensebarreres.es/	Associate
Spain	SIMA Asociación de afectados Síndrome de Marfan	http://www.marfan.es/	Full
Sweden	Agrenska	http://www.agrenska.se	Full
Sweden	Aorta Dissektion Föreningen Skandinavien	http://www.aortadissektion.com	Full
Sweden	DysNet	https://www.dysnet.org/	Full
Sweden	European Cavernoma Alliance	https://www.facebook.com/EuropeanCavernomaAlliance/	Associate
Sweden	Marfan Europe Network	http://www.marfan.eu	Full
Sweden	Neuroförbundet / Swedish Association Of Persons With Neurological Disabilities	http://neuroforbundet.se	Associate
Sweden	Prader Willi Syndrome Association In Sweden	http://www.prader-willi.se	Full
Sweden	Primär Immunbrist Organisationen	http://www.pio.nu	Full
Sweden	Rare Diseases Sweden (Riksförbundet Sällsynta Diagnoser)	http://www.sallsyntadiagnoser.se	Full
Sweden	Svensk förening för Hypoparatyreoidism	https://www.hypopara.se/	Associate
Sweden	Svenska Marfanföreningen - Swedish Marfan Assciation	http://www.marfanforeningen.se/	Full
Sweden	Svenska Ödemförbundet (Swedish Assocation of Chronic Oedema)	https://www.svenskaodemforbundet.se/	Associate
Sweden	Swedish Cystic Fibrosis Association	http://www.rfcf.se	Full
Sweden	Swedish EDS Association (EDS Riksförbund)	http://www.ehlers-danlos.se	Full
Sweden	Swedish MPS Society	http://www.mpsforeningen.se	Full
Sweden	Thyroid Federation International	http://www.thyroid-fed.org	Associate

Sweden	Wilhelm Foundation	http://www.wilhelmfoundation.org	Full
Switzerland	AGO2 Association	https://ago2.org/en	Associate
Switzerland	Association Enfance Et Maladies Orphelines	http://www.aemo.ch	Associate
Switzerland	Association Suisse Romande Intervenant contre les maladies Neuro-Musculaires	http://www.asrimm.ch	Full
Switzerland	Blackswan Foundation	http://www.blackswanfoundation.ch	Associate
Switzerland	CML Advocates Network	http://www.cmladvocates.net	Associate
Switzerland	Esperare	http://www.esperare.org	Associate
Switzerland	FMF & AID Global Association	http://www.fmfandaid.org	Associate
Switzerland	Fondation Sanfilippo Suisse	https://www.fondation-sanfilippo.ch/	Associate
Switzerland	Foundation Orphanhealthcare	http://www.orphanhealthcare.org/	Associate
Switzerland	Fraxas - Association X Fragile Suisse	http://www.fraxas.ch	Full
Switzerland	HAEi - Hereditary Angioedema International Association	http://www.haei.org	Associate
Switzerland	HHT-Swiss	http://www.hhtswiss.org	Associate
Switzerland	Maraval - Maladies Rares Valais - Seltene Krankheiten Wallis	http://www.maraval.ch/	Full
Switzerland	Marfan Foundation Switzerland (Marfan Stiftung Schweiz)	http://www.marfan.ch	Full
Switzerland	Prader Willi Syndrom Vereinigung Schweiz	http://www.prader-willi.ch	Full
Switzerland	Proraris	http://www.proraris.ch	Full
Switzerland	Schweizerische Gesellschaft Für Porphyrie	http://www.porphyria.ch	Full
Switzerland	Selbsthilfe Ichthyose Schweiz	http://www.ichthyose.ch	Associate
Switzerland	Sjögren Europe	http://sjogreneurope.org/	Associate
Switzerland	SMA Schweiz	http://www.sma-schweiz.ch	Associate
Switzerland	Swiss FH/Schweizerische Gesellschaft für familiäre Formen der Hypercholesterinämie	http://www.sgfh.ch	Associate
Taiwan, Province of China	Taiwan Foundation For Rare Disorders	http://www.tfrd.org.tw	Associate
Turkey	DMD Aileleri Derneği	https://www.dmdaileleri.org/	Full
Turkey	Duchenne Kas Hastalığı İle Mücadele Derneği	http://dmdturkiye.org/	Full
Turkey	Kifder	http://www.kifder.org.tr	Associate
Turkey	Mukopolisakkaridoz ve Benzeri Lizozomal Depo Hastalıkları Derneği / MPS Turkey	http://www.mpsturk.org	Associate
Turkey	Pulmoner Hipertansiyon ve Skleroderma Hasta Derneği / PHA Turkey	http://www.pahssc.org.tr	Full
Turkey	Sistinozis Hastaları Derneği / Cystinosis Patients Association	https://www.sistinder.org/	Associate
Turkey	SMA Hastalığı İle Mücadele Derneği	http://www.sma.org.tr	Full
Turkey	Yuzumle Mutluyum Derneği/Happy Faces	http://www.yuzumlemutluyum.org.tr	Associate
Ukraine	Association of Patients with Pulmonary Hypertension	http://www.pha.org.ua	Full
Ukraine	Children with Spinal Muscular Atrophy, Charitable Foundation	http://www.csma.org.ua	Full

Ukraine	LCCF "Sister Dalila" Pulmonary Hypertension Ukrainian Rare Disease Association	http://poryatunok.info/uk/	Full
Ukraine	NGO "Rare Diseases of Ukraine"	https://www.facebook.com/orphandisua/	Associate
Ukraine	Ukrainian Association Crystal People	http://ostimperfecta.wix.com/oiua	Associate
Ukraine	Ukrainian Association of Help for Patients with CF	http://facebook.com/cysticfibrosisua	Full
Ukraine	Ukrainian National Charitable Fund Zaporuka	http://www.zaporuka.com.ua	Associate
Ukraine	Ukrainian Union Of Patients' Organisations	https://patients.org.ua/en/	Associate
Ukraine	Ukrainian Parent Project "Mio-Life"	http://miolife.org	Associate
United Kingdom of Great Britain and Northern Ireland	Acrodysostosis Support and Research	http://www.acrodysostosis.com	Associate
United Kingdom of Great Britain and Northern Ireland	Action Duchenne	http://www.actionduchenne.org	Full
United Kingdom of Great Britain and Northern Ireland	Advocacy For Neuroacanthocytosis Patients	http://www.naadvocacy.org	Associate
United Kingdom of Great Britain and Northern Ireland	AKU Society	http://www.akusociety.org	Full
United Kingdom of Great Britain and Northern Ireland	Alex, the Leukodystrophy Charity,	https://www.alextlc.org/	Associate
United Kingdom of Great Britain and Northern Ireland	Alstrom Syndrome Europe	https://www.alstrom.org.uk/as-europe/	Associate
United Kingdom of Great Britain and Northern Ireland	Alstrom Syndrome UK	http://www.alstrom.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Ann Edgar Charitable Trust - Neuroendocrine Tumour Support	http://www.taect.scot	Full
United Kingdom of Great Britain and Northern Ireland	Annabelle's Challenge	http://www.annabelleschallenge.org	Full
United Kingdom of Great Britain and Northern Ireland	Association for Glycogen Storage Disease	http://www.agsd.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Association for Multiple Endocrine Neoplasia Disorders	http://www.amend.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Ataxia UK	http://www.ataxia.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Batten Disease Family Association	http://www.bdfa-uk.org.uk/about-batten-disease	Full
United Kingdom of Great Britain and Northern Ireland	Behcet's UK	http://www.behcets.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Brittle Bone Society	http://www.brittlebone.org	Associate

United Kingdom of Great Britain and Northern Ireland	Cambridge Rare Disease Network	http://www.camraredisease.com	Associate
United Kingdom of Great Britain and Northern Ireland	Cancer 52	http://www.cancer52.org.uk	Associate
United Kingdom of Great Britain and Northern Ireland	Cavernoma Alliance UK	http://www.cavernoma.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	CDH International	https://cdhi.org/	Full
United Kingdom of Great Britain and Northern Ireland	CDH UK	http://www.cdruk.org.uk/	Full
United Kingdom of Great Britain and Northern Ireland	Child Growth Foundation	http://www.childgrowthfoundation.org	Full
United Kingdom of Great Britain and Northern Ireland	Child Lung Foundation	http://www.childlungfoundation.org	Associate
United Kingdom of Great Britain and Northern Ireland	Childhood Tumor Trust	https://www.childhoodtumourtrust.org.uk/	Full
United Kingdom of Great Britain and Northern Ireland	Children's Liver Disease Foundation	http://www.childliverdisease.org	Associate
United Kingdom of Great Britain and Northern Ireland	Ciliopathy Alliance	http://www.ciliopathyalliance.org	Full
United Kingdom of Great Britain and Northern Ireland	Contact A Family	http://www.cafamily.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Cure CLCN4	https://cureclcn4.org/	Associate
United Kingdom of Great Britain and Northern Ireland	Cystinosis Foundation of the UK	http://www.cystinosis.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Dancing Eye Syndrome Support Trust	http://www.dancingeyes.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Degos Disease Support Network	http://www.degosdisease.com	Associate
United Kingdom of Great Britain and Northern Ireland	Ectodermal Dysplasia Society	https://edsociety.co.uk/	Full
United Kingdom of Great Britain and Northern Ireland	Euro Ataxia - European Federation of hereditary Ataxias	http://www.euroataxia.org	Full
United Kingdom of Great Britain and Northern Ireland	European Lung Foundation	http://www.european-lung-foundation.org/	Associate
United Kingdom of Great Britain and Northern Ireland	European Myasthenia Gravis Association	http://www.eumga.eu	Associate

United Kingdom of Great Britain and Northern Ireland	European Tuberous Sclerosis Complex Association	http://www.e-tsc.eu	Full
United Kingdom of Great Britain and Northern Ireland	Fabry International Network	http://www.fabrynetwork.org/	Full
United Kingdom of Great Britain and Northern Ireland	Fetal Anti Convulsant Syndrome Association		Associate
United Kingdom of Great Britain and Northern Ireland	FH Europe	https://www.fheurope.org/	Associate
United Kingdom of Great Britain and Northern Ireland	Findacure: The Fundamental Diseases Partnership	http://www.findacure.org.uk	Associate
United Kingdom of Great Britain and Northern Ireland	FOP Friends	http://www.fopfriends.com	Full
United Kingdom of Great Britain and Northern Ireland	Gauchers Association UK	http://www.gaucher.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Genetic Alliance UK	http://www.geneticalliance.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Glut1 Deficiency UK	http://www.glut1deficiency.org.uk	Associate
United Kingdom of Great Britain and Northern Ireland	Hope for Hasti	https://www.hopeforhasti.org/	Associate
United Kingdom of Great Britain and Northern Ireland	Hope for Hypothalamic Hamartomas UK	http://www.hopeforhh.org	Full
United Kingdom of Great Britain and Northern Ireland	Huntington's Disease Youth Organisation	https://en.hdyo.org/	Full
United Kingdom of Great Britain and Northern Ireland	International Brain Tumour Alliance	http://www.theibta.org	Associate
United Kingdom of Great Britain and Northern Ireland	International Gaucher Alliance	https://gaucheralliance.org/	Full
United Kingdom of Great Britain and Northern Ireland	International Niemann-Pick Disease Alliance	http://www.inpda.org	Full
United Kingdom of Great Britain and Northern Ireland	International Patient Organization for Primary Immunodeficiencies	http://www.ipopi.org	Full
United Kingdom of Great Britain and Northern Ireland	International Prader-Willi Syndrome Organisation	http://www.ipwso.org	Full
United Kingdom of Great Britain and Northern Ireland	Joining Jack	http://www.joiningjack.org	Full
United Kingdom of Great Britain and Northern Ireland	Krabbe UK	https://www.krabbeuk.org/	Full

United Kingdom of Great Britain and Northern Ireland	Leber's Hereditary Optic Neuropathy Society	http://www.lhonsociety.org	Full
United Kingdom of Great Britain and Northern Ireland	LGD Alliance Europe	http://www.lgda.eu	Full
United Kingdom of Great Britain and Northern Ireland	Max Appeal	http://www.maxappeal.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Mebo Research	http://www.meboresearch.org	Associate
United Kingdom of Great Britain and Northern Ireland	Metabolic Support UK	http://www.metabolicsupportuk.org	Full
United Kingdom of Great Britain and Northern Ireland	MPS Society	https://www.mpssociety.org.uk/	Full
United Kingdom of Great Britain and Northern Ireland	Myotubular Trust	http://www.myotubulartrust.org	Full
United Kingdom of Great Britain and Northern Ireland	Niemann-Pick Disease Group UK	http://www.npuk.org	Full
United Kingdom of Great Britain and Northern Ireland	Northern Ireland Rare Disease Partnership	http://www.nirdp.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Organisation For Anti-Convulsant Syndrome	http://www.oacscharity.org	Full
United Kingdom of Great Britain and Northern Ireland	Pitt Hopkins UK	http://pitthopkins.org.uk/	Full
United Kingdom of Great Britain and Northern Ireland	Polycystic Kidney Disease Charity	https://pkdcharity.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Pompe Support Network	https://pompe.uk/	Associate
United Kingdom of Great Britain and Northern Ireland	PSC Support	http://www.pscsupport.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Pseudomyxoma Survivor	http://www.pseudomyxomasurvivor.co.uk	Associate
United Kingdom of Great Britain and Northern Ireland	Pten Research Foundation	http://www.ptenresearch.org	Associate
United Kingdom of Great Britain and Northern Ireland	Rare Autoinflammatory Conditions Community- UK	http://www.raccuk.com	Associate
United Kingdom of Great Britain and Northern Ireland	Rare Diseases UK	http://www.raredisease.org.uk	Associate
United Kingdom of Great Britain and Northern Ireland	Ring 20 Research and Support UK CIO	http://ring20researchsupport.co.uk/	Associate

United Kingdom of Great Britain and Northern Ireland	Salivary Gland Cancer UK	https://www.salivaryglandcancer.uk/	Associate
United Kingdom of Great Britain and Northern Ireland	Schinzel-Giedion Syndrome Foundation	https://sgsfoundation.org/	Associate
United Kingdom of Great Britain and Northern Ireland	Smile with Shiv	http://smilewithshiv.org/	Associate
United Kingdom of Great Britain and Northern Ireland	Spinal Muscular Atrophy Support UK	http://www.smasupportuk.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	Stiff Person Support Group	http://www.smssupportgroup.co.uk	Full
United Kingdom of Great Britain and Northern Ireland	Sturge-Weber UK	http://www.sturgeweber.org.uk	Full
United Kingdom of Great Britain and Northern Ireland	The AADC Research Trust Children's Charity	http://www.aadcresearch.org	Full
United Kingdom of Great Britain and Northern Ireland	The Aarskog Foundation	http://www.aarskogsyndrome.foundation.co.uk	Associate
United Kingdom of Great Britain and Northern Ireland	The Chromosome 18 Registry And Research Society (Europe)	http://www.chromosome18eur.org	Associate
United Kingdom of Great Britain and Northern Ireland	The Cure & Action For Tay-Sachs (Cats) Foundation	http://www.cats-foundation.org	Full
United Kingdom of Great Britain and Northern Ireland	The EHE Rare Cancer Charity	https://www.ehercc.org.uk/	Full
United Kingdom of Great Britain and Northern Ireland	The Ehlers-Danlos Society	http://ehlers-danlos.com/	Full
United Kingdom of Great Britain and Northern Ireland	The Fragile X Society	http://www.fragilex.org.uk/	Full
United Kingdom of Great Britain and Northern Ireland	The Maddi Foundation	http://themaddifoundation.com/	Associate
United Kingdom of Great Britain and Northern Ireland	The PBC Foundation (UK) Ltd	http://www.pbcfoundation.org.uk	Associate
United Kingdom of Great Britain and Northern Ireland	Timothy Syndrome Alliance	https://timothysyndrome.org.uk/	Associate
United Kingdom of Great Britain and Northern Ireland	Tuberous Sclerosis Association	http://www.tuberous-sclerosis.org	Full
United Kingdom of Great Britain and Northern Ireland	UK ATTR Amyloidosis Patients' Association	https://ttramylodosis.uk/	Associate
United Kingdom of Great Britain and Northern Ireland	UK Mastocytosis Support Group	http://www.ukmasto.org	Full

United Kingdom of Great Britain and Northern Ireland	Unique - Rare Chromosome Disorder Support Group	http://www.rarechromo.org	Full
United Kingdom of Great Britain and Northern Ireland	United Kingdom Thalassaemia Society	http://www.ukts.org	Full
United Kingdom of Great Britain and Northern Ireland	Vasculitis UK (The Vasculitis Trust)	http://www.vasculitis.org.uk	Full
United States of America	Alagille Syndrome Alliance	http://www.alagille.org	Associate
United States of America	Alstrom Syndrome International	http://www.alstrom.org	Associate
United States of America	APS Foundation of America, Inc	http://www.apsfa.org	Associate
United States of America	Association for Creatine Deficiencies	https://creatineinfo.org/	Associate
United States of America	BCM Families Foundation	http://www.blueconermonochromacy.org/	Associate
United States of America	CACNA1A Foundation	https://www.cacna1a.org/	Associate
United States of America	Cure PSP	http://www.curepsp.org	Associate
United States of America	Cystinosis Foundation	http://www.cystinosisfoundation.org	Associate
United States of America	Defeat MSA Alliance	https://defeatmsa.org	Associate
United States of America	Empty Nose Syndrome International Association	https://www.facebook.com/ENSIAssociation/	Associate
United States of America	FMD Chat	http://fmdchat.blogspot.fr/	Associate
United States of America	Global Dare Foundation	https://www.defeatadultrefsumeverywhere.org/	Associate
United States of America	Gould Syndrome Foundation	http://www.gouldsyndrome.foundation.org/	Associate
United States of America	International Foxg1 Foundation	http://foxg1.org	Associate
United States of America	International Pemphigus & Pemphigoid Foundation	http://www.pemphigus.org	Associate
United States of America	International WAGR Syndrome Association	http://wagr.org/	Associate
United States of America	International Waldenstrom's Macroglobulinemia Foundation	http://www.iwmf.com	Associate
United States of America	MCT8-AHDS Foundation Inc.	http://www.mct8.info	Associate
United States of America	Myhre Syndrome Foundation	https://www.myhresyndrome.org/	Associate
United States of America	Neuromuscular Disease Foundation	https://curegnem.org/	Associate
United States of America	Nord National Organization for Rare Disorders	http://www.rarediseases.org	Associate
United States of America	NTM Info & Research	http://www.ntminfo.org	Associate
United States of America	Project 8p	https://project8p.org/	Associate
United States of America	PTEN Hamartoma Tumor Syndrome Foundation	http://www.ptenfoundation.org	Associate
United States of America	Pura Syndrome Foundation	http://www.purasyndrome.org	Associate
United States of America	Remember The Girls	https://rememberthegirls.org/	Associate
United States of America	SATB2 Gene Foundation	https://satb2gene.org/	Associate
United States of America	STXBP1 Foundation	https://www.stxbp1disorders.org/	Associate
United States of America	Superficial Siderosis Research Alliance	https://ssra.livingwithss.com/	Associate
United States of America	SYNGAP1 Foundation	http://www.bridgesyngap.org	Associate

United States of America	The Cushing Support & Research Foundation	http://www.csrf.net	Associate
United States of America	The Cute Syndrome Foundation	https://www.thecutesyndrome.com/	Associate
United States of America	The Oxalosis & Hyperoxaluria Foundation	http://www.ohf.org	Associate
United States of America	The Snyder-Robinson Foundation	https://snyder-robinson.org/	Associate
United States of America	Usher Syndrome Coalition	http://www.usher-syndrome.org	Associate
Uruguay	Asociacion Acondroplasia Uruguay	https://www.facebook.com/acondroplasia.uruguay/	Associate
Uruguay	Fundacion Uruguaya para la Investigacion de las Enfermedades Raras	http://www.fupier.org/	Associate
Venezuela, Bolivarian Republic of	Fundación Fura	http://fundacion-fura.mozello.com	Associate
Zimbabwe	Child & Youth Care, Zimbabwe	http://www.cyc.org.zw/	Associate