

EURORDIS Member Associations - July 2018



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

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

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

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

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

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

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

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

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

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

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

Hungary	Rare Diseases Hungary - RIROSZ	www.rirosz.hu	Full Member
Iceland	AHC Federation of Europe	www.ahcfe.eu	Associate member
Iceland	Alternating Hemiplegia of Childhood association of Iceland	www.ahc.is	Full member
Iceland	Einstok Born - Support Group for Children with Rare Disorders	www.einstokborn.is/	Full Member
Iceland	Gudrun's Rett Syndrome Research Trust	rettenglar.yolasite.com	Associate member
Iceland	Hypoparathyroidism Europe (HPTH Europe)		Associate Member
Iceland	The Icelandic Childhood Cancer Parent Organization	www.skb.is	Full Member
India	Indian Organization for Rare Diseases	www.I-ORD.org	Associate member
India	Organization for Rare Diseases India	www.ordindia.org	Associate member
Iran	Charity Foundation for Special Diseases	www.cffsd.org	Associate member
Iran	Rare Disease Foundation of Iran	http://radoir.com	Associate member
Ireland	22q11 Ireland Support Group	www.22q11ireland.org	Full member
Ireland	Alpha One Foundation	www.alpha1.ie	Full Member
Ireland	Barretstown Serious Fun	www.barretstown.org	Associate member
Ireland	Cystic Fibrosis Ireland	www.cfireland.ie	Associate member
Ireland	Cystinosis Ireland	cystinosis.ie	Full member
Ireland	Fighting Blindness	www.fightingblindness.ie	Full Member
Ireland	Friedreich's Ataxia Research Alliance	www.faraireland.ie	Full member
Ireland	Huntington's Disease Association of Ireland	www.huntingtons.ie	Full Member
Ireland	Irish Cancer Society	www.cancer.ie	Associate member
Ireland	Muscular Dystrophy Ireland	www.mdi.ie	Full Member
Ireland	Neurofibromatosis Association of Ireland	www.nfaireland.ie	Full Member
Ireland	PoPSyCLE Foundation	https://www.facebook.com/Popsycle01/	Associate member
Ireland	Rare Diseases Ireland	http://rdi.ie/	Full Member
Ireland	Sickle Cell and Thalassaemia Ireland	www.sicklecellireland.ie	Full member
Ireland	Syringomyelia Ireland	www.syringomyelia.ie	Full Member
Ireland	The Cavan Tommy Hoey Trust	http://www.the-cavan-tommy-hoey-trust.org.uk/page1.php	Associate member
Ireland	The Irish Fragile X Society	http://fragilexireland.org	Full member
Israel	Israel Adult Polyglucosan Body Disease		Associate member
Italy	ABC Associazione Bambini Cri du Chat	www.criduchat.it	Full member
Italy	Acondroplasia - Insieme per crescere - Onlus	www.acondroplasia-insiemepercrescere.it	Full member
Italy	AIBWS Onlus	www.aibws.org	Full member
Italy	Amici della Porfiria - San Pio da Pietrelcina Onlus	www.porfiria.it	Associate member
Italy	Angeli Noonan	www.angelinoonan.it	Full member
Italy	Associazione Persone con Malattie Reumatiche – APMAR Onlus	www.apmar.it	Full member
Italy	Associazione Conto Alla Rovescia	www.acar2006.org	Full member

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

Italy	Associazione Sclerosi Tuberosa	www.sclerosituberosa.org	Full Member
Italy	Associazione Sindrome Nefrosica Italia	www.asnit.org	Full member
Italy	Associazione Studio Malattie Metaboliche Ereditarie Onlus	www.cometaasmme.org	Full Member
Italy	Associazione Veneta per la Lotta alla Talassemia	www.avlt.it	Full Member
Italy	CIDP Italia Onlus	www.cidp.it	Full member
Italy	Collagene VI Italia Onlus - COL6	www.col6.it	Full member
Italy	costello.cfc - associazione italiana sindrome di costello - cardiofaciocutanea - rasopatie - onlus	www.sindromedicostello.it	Full member
Italy	DEBRA Italia ONLUS – Associazione per la Ricerca sull'Epidermolisi Bollosa	www.debraitaliaonlus.org	Full Member
Italy	Dravet Italia Onlus	www.dravet-italia.org	Full member
Italy	Federazione Nazionale Prader Willi	www.praderwilli.it	Full Member
Italy	FOP Italia Onlus	www.fopitalia.it	Full member
Italy	Gli amici di Daniela	www.amicididaniela.it	Associate member
Italy	Gruppo Italiano per la Lotta alla Sclerodermia ONLUS	www.sclerodermia.net	Full member
Italy	HHT Europe	www.hhteurope.org	Full member
Italy	Incontinentia Pigmenti Associazione Italiana Onlus	www.incontinentiapigmenti.it	Associate member
Italy	Lega Italiana Sclerosi Sistemica Onlus	www.sclerosistemica.info	Full member
Italy	Lega per la Neurofibromatosi 2-Onlus	www.neurofibromatosi2.it	Full member
Italy	LND Famiglie Italiane Onlus	www.lnd-it.com	Full member
Italy	p63 EEC Syndrome International net work word communication - MALATTIE RARE ONLUS	www.sindrome-eec.it	Associate member
Italy	Pandas Italia	www.pandasitalia.com	Full member
Italy	Parent Project Onlus	www.parentproject.it	Full Member
Italy	PKS Kids Italia Onlus	www.pksitalia.org	Full member
Italy	Retina Italia onlus	http://www.retinaitalia.org/	Full member
Italy	Ring 14 International	www.ring14.org	Full member
Italy	SOD Italia - Associazione Italiana Displasia Setto Ottica e Ipoplasia del Nervo Ottico	www.soditalia.it	Full member
Italy	UNIAMO - Rare Diseases Italy	www.uniamo.org	Full Member
Italy	Unione Italiana Ittiosi	http://www.ittiosi.it	Full Member
Italy	United Onlus	www.unitedonlus.org	Full member
Italy	Visus - Associazione tra affetti aa Retinite Pigmentosa		Full Member
Italy	XLPDR International Association	www.xlpdr.com	Associate member
Japan	Japan Patient Association	www.nanbyo.jp	Associate member
Kazakhstan	Patients with cancer and rare diseases support association		Associate member
Latvia	Association of people with special needs "Motus Vita"	http://www.motusvita.lv/index.php?lang=en	Associate member
Latvia	Empty Nose Syndrome International Association	ensassociation.org	Associate member

Latvia	Latvian Alliance for Rare Diseases	www.retasslimibas.lv	Associate member
Latvia	Rare Disease Association "Caladius"		Associate member
Lebanon	Lebanese association for neuromuscular diseases	landforhope.org	Associate member
Lithuania	Association for Children Rare Diseases	www.retosligos.lt	Associate member
Lithuania	Community of Oncohematological Patient Organisations KRAUJAS	www.kraujas.lt	Full member
Luxembourg	ALAN - Maladies Rares Luxembourg	www.alan.lu	Full Member
Luxembourg	den i asbl Syndrome de Marfan	www.den-i.lu/	Associate member
Luxembourg	Een Häerz Fir Kriibskrank Kanner Asbl	www.kriibskrankkanner.lu	Full member
Luxembourg	Fondatioun Kriibskrank Kanner	www.fondatioun.lu	Associate member
Luxembourg	Rett Syndrome Europe	www.rettsyndrome.eu	Full member
Malaysia	Malaysia Metabolic Society	www.mms.my	Associate member
Malaysia	Malaysian Rare Disorders Society	www.mrds.org.my	Associate member
Malta	National Alliance for Rare Diseases Support - Malta	www.rarediseasesmalta.com	Associate member
Mexico	Proyecto Pide un Deseo Mexico iap	www.pideundeseo.org	Associate member
Mexico	Red Sanfilippo	www.redsanfilippo.org	Associate member
Moldova	Copiii ploii	https://www.facebook.com/AO-Copiii-Ploii-686485228086936/	Full member
Montenegro	National Organisation for Rare Diseases	www.rijetkebolesti.com	Associate member
Morocco	Association Marocaine de la Fièvre Méditerranéenne Familiale et des autres fièvres récurrentes		Associate member
Morocco	Sun'Hop		Associate member
Nepal	GBS/CIDP Foundation Nepal	www.gbs-cidp-nepal.org/	Associate member
Netherlands	ALS Patients Connected	www.alspatientsconnected.com	Full member
Netherlands	Autosomaal Dominant Cerebellaire Ataxie-Vereniging Nederland	www.ataxie.nl	Full Member
Netherlands	Bijniervereniging NVACP	www.nvacp.nl	Full Member
Netherlands	Childhood Cancer International	www.childhoodcancerinternational.org	Full member
Netherlands	CMTC-OVM	www.cmtc.nl	Full Member
Netherlands	Cornelia de Lange Syndrome World Federation	www.cdlsworld.org	Full member
Netherlands	European Society for Phenylketonuria	www.espk.org	Associate member
Netherlands	European VHL (von Hippel-Lindau) Federation	www.vhl-europa.org	Associate member
Netherlands	European Waldenström Macroglobulinemia Network	www.waldenstrom.eu	Full member
Netherlands	Fabry Support & Informatie Groep Nederland	www.fabry.nl	Full member
Netherlands	Fibrodysplasia Ossificans Progressiva Stichting Nederland	www.fopstichting.nl	Full member
Netherlands	FSHD Europe	http://fshd-europe.info	Full member
Netherlands	International Mito Patients	www.mitopatients.org	Full member
Netherlands	International Painful Bladder Foundation	www.painful-bladder.org	Associate Member

Netherlands	International Porphyria Patient Network	www.ippn.info	Associate member
Netherlands	Interstitiële cystitis Patientenvereniging	www.icpatienten.nl	Full member
Netherlands	ITP Patientenvereniging	www.itp-pv.nl	Full member
Netherlands	KAISZ children with a autoimmune or autoinflammatory disease	www.kaisz.nl	Full member
Netherlands	MSS (Marshall-Smith Syndrome) Research Foundation	www.marshallsmith.org	Full member
Netherlands	Nederlands Netwerk voor Lymfoedeem en Lipoedeem	www.lymfoedeem.nl	Associate member
Netherlands	Nederlandse Hypofyse Stichting (Dutch Pituitary Foundation)	www.hypofyse.nl	Full member
Netherlands	Nederlandse Phenylketonurie Vereniging / Dutch PKU Association	Www.pkuvereniging.nl	Full member
Netherlands	NephcEurope	http://nephceurope.eu/nc/	Associate member
Netherlands	Netherlands Liver Patients Association	www.leverpatientenvereniging.nl	Full member
Netherlands	Neurofibromatose Vereniging Nederland	www.neurofibromatose.nl	Full member
Netherlands	OSCAR Nederland	www.oscarnederland.nl	Full member
Netherlands	Patientenorganisatie Fibreuze Dysplasie	http://www.fibreuzedysplasie.eu	Full member
Netherlands	PSC Patients Europe	http://pscpatientseurope.org	Full member
Netherlands	Sarcoidose.nl	www.sarcoidose.nl	Full member
Netherlands	Stichting AA & PNH contactgroep	http://www.aaenph.nl	Full member
Netherlands	Stichting Amyloidose Nederland SAN	amyloidose.nl	Full member
Netherlands	Stichting Christianson Syndrome Europe	https://cs-europe.org/nl/	Associate member
Netherlands	Stichting Hart4Onderzoek / Heart4Research	http://www.hart4onderzoek.nl/over- een.html	Associate member
Netherlands	Stichting Histiocytose Nederland	www.histio.nl	Full Member
Netherlands	Stichting Ijzersterk	www.stichtingijzersterk.nl	Associate member
Netherlands	Stichting NET-groep	www.net-kanker.nl	Full member
Netherlands	Stichting Shwachman Diamond Syndrome Support Holland	www.shwachman.nl	Full member
Netherlands	Stichting Stofwisselkracht	www.stofwisselkracht.nl	Full member
Netherlands	Stichting Terre - Rett Syndrome Foundation	www.stichtingterre.nl	Full member
Netherlands	STICHTING VOOR AFWEERSTOORNISSEN	www.stichtingvoorafweerstoornissen.nl	Full Member
Netherlands	Thyroid Cancer Alliance	www.thyroidcanceralliance.org	Full member
Netherlands	United Parent Projects Muscular Dystrophy	www.uppmd.org	Full member
Netherlands	Vasculitis Stichting (formerly known as Friedrich Wegener Stichting)	www.vasculitis.nl	Full member
Netherlands	Vereniging Spierziekten Nederland - Dutch Association For Neuromuscular Disease	www.vsn.nl	Full member
Netherlands	Volwassenen, Kinderen en Stofwisselingsziekten	www.stofwisselingsziekten.nl	Full Member
Netherlands	VSOP - Vereniging Samenwerkende Ouder En Patiëntenorganisaties	www.vso.nl	Full Member
Netherlands	World Alliance of Pituitary Organizations	www.wapo.org	Associate member
New Zealand	New Zealand Organisation for Rare Disorders	www.nzord.org.nz/	Associate Member

Norway	Aniridi Norge	www.aniridi.no	Full member
Norway	Aniridia Europe	www.aniridia.eu	Full member
Norway	European Huntington Association	http://eurohuntington.org/	Full member
Norway	FRAMBU - Resource Centre for Rare Disorders	www.frambu.no	Full member
Norway	Morbus Addison Association Norway	www.addison.no	Full member
Norway	MPS foreningen Norge		Associate member
Norway	Nordic hypoPARA Organisation	www.hypopara-nordic.org	Full Member
Norway	Norsk forening for Arvelig Spastisk Paraparese / Ataksi	www.naspa.no	Full member
Norway	NORSK FORENING FOR EHLERS-DANLOS SYNDROM	www.eds-foreningen.no	Full Member
Norway	Norsk Forening for Osteogenesis Imperfecta	www.nfoi.no	Full member
Norway	Norsk Forening for Tuberos Sklerose	www.nfts.no	Full member
Norway	Oslerforeningen Norge	www.osler.no	Full member
Poland	Debra Polska	www.debra-kd.pl	Full member
Poland	Fundacja Sanfilippo	www: sanfilippo.org.pl	Associate member
Poland	Fundacja SMA (SMA Foundation Poland)	www.fsma.pl	Full member
Poland	Fundacja Umieć Pomagać (Foundation for RD MPS)	www.umiecpomagac.org	Full member
Poland	MATIO-Fundacji Pomocy Rodzinom i Chorym na Mukowiscydozę	www.mukowiscydoza.pl	Full Member
Poland	Polish National Forum on the Treatment of Orphan Diseases - ORPHAN	www.rzadkiechoroby.pl	Full member
Poland	Polish PKU and RD Association "Ars Vivendi"	www.fenyloketonuria.org	Full member
Poland	Polish Society of MPS and Related Diseases	www.mps-society.pl	Full member
Poland	Polskie Stowarzyszenie na Rzecz Osób z AHC		Associate member
Poland	The Dina Radziwillowa Child's Heart Foundation	www.sercedziecka.org.pl	Full member
Portugal	Aliança Portuguesa de Associações das Doenças Raras	http://aliancadoencasraras.org/	Associate member
Portugal	APLL - Associação Portuguesa de Leucemias e Linfomas	www.apll.org	Full member
Portugal	Associação Nacional de Displasias Ósseas	www.andoportugal.org	Associate member
Portugal	Associação Portuguesa CDG e outras Doenças Metabólicas	www.apcdg.com	Associate member
Portugal	Associação Portuguesa de Charcot-Marie-Tooth	apcmt.org.pt	Full member
Portugal	ASSOCIAÇÃO PORTUGUESA DE DOENTES NEUROMUSCULARES	www.apn.pt	Full Member
Portugal	Associação Portuguesa de Osteogénese Imperfeita	www.apoi.pt	Full member
Portugal	Associação Sanfilippo Portugal	www.sanfilippoportugal.com	Full member
Portugal	FEDRA - Federação Portuguesa de Doenças Raras (suspended)	www.fedra.pt	Associate member

Portugal	Rarissimas - Associacao Nacional de Deficiencias Mentais e Raras	www.rarissimas.pt	Associate member
Romania	Asociatia Copilul Meu-Inima Mea	www.acmim.ro	Full member
Romania	Asociatia Persoanelor Cu Talasemie Majora	www.talasemia.ro	Full member
Romania	Asociația Română de Cancere Rar	www.arcrareromania.ro	Associate member
Romania	Asociatia Romana Spina Bifida si Hidrocefalie	www.arsbh.ro	Associate member
Romania	Asociatia Werdnig Hoffman AWH	www.werdnighoffman.ro	Full member
Romania	Asociatia Williams Syndrome	www.williams-syndrome.ro	Full Member
Romania	Autoimmune Diseases Patients Association	www.apaa.ro	Associate member
Romania	Mastocytosis Support Association Romania	www.mastocitoza.ro	Associate member
Romania	Romanian Myasthenia Gravis Association	www.miastenie.ro	Full member
Romania	Romanian National Alliance for Rare Diseases	bolirareromania.ro	Full member
Romania	Romanian Prader Willi Association	www.apwromania.ro	Full Member
Russian Federation	Fabry Russia	www.fabryrufa.ru	Associate member
Russian Federation	Help to Cystic Fibrosis Patients		Full member
Russian Federation	Interregional public organisation for Gaucher disease	www.gaucher.ru	Full member
Russian Federation	Interregional Public Organisation of patients with Fabry Disease "The Road to Life"	www.fabryufa.ru	Full member
Russian Federation	MPS Russia	www.mps-russia.org	Full member
Russian Federation	National Association of Patients with Rare Diseases "GENETICA"	www.nacgenetic.ru	Associate member
Russian Federation	NGO "Fragile children"	www.osteogenez.ru	Full member
Russian Federation	Russian association of rare diseases	www.rare-diseases.ru	Full member
Russian Federation	Russian Interregional public organization "Inter-regional support centre for patients with Aniridia " Iris"	www.aniridia.ru	Associate member
Russian Federation	Russian Patient Union	http://www.patients.ru/en	Associate member
Russian Federation	Russian Rett Syndrome Asociation	www.rettsyndrome.ru	Associate member
Russian Federation	SPIPORZ Union of patients with rare diseases and rare disease patients organsiations	www.spiporz.ru	Associate member
Russian Federation	The Association of primary immunodeficiency patients	www.oppid.ru	Full member
Serbia	Child rare disease support and research association Life	www.zivotorg.org	Associate member
Serbia	Childhood Cancer Parent Organisation "Zvoncica"		Full member
Serbia	Lymphoma Patients' Association	www.lipa.org.rs	Associate member
Serbia	National Organization for Rare Diseases, Serbia	www.norbs.rs	Full member
Singapore	Rare Disorders Society (Singapore)	www.rdss.org.sg	Associate member
Slovakia	Debra SR	www.debra-slovakia.org	Full member
Slovakia	Organisation of Muscular Dystrophy in the Slovak Republic	www.omdvsr.sk	Full member
Slovakia	Slovak Alliance of Rare Diseases	www.sazch.sk	Associate member

Slovakia	Slovak Cystic Fibrosis Association	www.cfasociacia.sk	Full member
Slovakia	Zdruzenie Ojedlinelych Genetickyh Ochorenie	http://www.zogo.sk/	Associate member
Slovenia	Association of patients with blood diseases - Drustvo Bolnikov S Krvnimi Boleznimi	www.drustvo-bkb.si	Full member
Slovenia	Debra Slovenia - Drustvo DEBRA Slovenija	www.debra-slovenia.si	Full member
Slovenia	EAMDA - European Alliance of Neuromuscular Disorders Associations	www.eamda.eu	Full Member
Slovenia	Fabry Patients Association Slovenia / Društvo bolnikov s Fabryjevo boleznijo Slovenije		Full member
Slovenia	Foundation of Child Neurology	http://peunevro.peukr.si/english/foundation/	Associate Member
South Africa	Primary Immunodeficiency Network of South Africa	www.pinsa.org.za	Associate member
South Africa	Rare Disease Society of South Africa	www.rarediseases.co.za	Associate member
Spain	Acción y Cura para Tay-Sachs - ACTAYS	www.actays.org	Full member
Spain	Alianza Española de Familias de Von Hippel Lindau	www.alianzavhl.org	Full Member
Spain	Asociació Catalana de las Neurofibromatosis	http://www.acnefi.com/castella/gamhome.htm	Full Member
Spain	Asociació d'Afectats de Siringomièlia	www.siringomielia.org	Full Member
Spain	Asociación Andaluza contra la Fibrosis Quística	www.fibrosisquistica.org/andaluza/	Full Member
Spain	Asociación Andaluza de Pacientes con Síndrome de Tourette y Trastornos Asociados	www.tourette.es	Full Member
Spain	Asociación Artrogriposis Múltiple Congénita	www.amc-esp.blogspot.com	Full member
Spain	Asociacion Chiari y Siringomielia del Principado de Asturias	www.chyspa.org	Full member
Spain	Asociación de Afectados de Neurofibromatosis	www.neurofibromatosis.es	Full member
Spain	Asociación de Afectados por Displasia Ectodérmica	www.displasiaectodermica.org	Full member
Spain	Asociación de Afectados por Hiperinsulinismo Congénito	www.afhico.org	Full member
Spain	Asociacion de Atrofia de Nervio Optico de Leber	www.asanol.com	Full member
Spain	Asociación de Epidermolisis Bullosa de España (DEBRA España)	www.debra.es	Full member
Spain	Asociación de Esclerodermia Castellon	www.esclerodermia-adec.org	Full Member
Spain	Asociacion de Familiares y afectados por Lipodistrofias	www.aelip.org	Full member
Spain	Asociacion de Familiares y Enfermos de FPI y FPF	www.afefpi.org	Full member
Spain	Asociación de Hemoglobinuria Paroxística Nocturna	www.hpne.org	Associate member
Spain	Asociación de Huesos de Cristal de España	www.ahuce.org	Full Member
Spain	Asociación de las Mucopolisacaridosis y Síndromes Relacionados	www.mpsesp.org/	Full Member
Spain	Asociación de Nevus Gigante Congénito	http://asonevus.org/	Full Member

Spain	Asociacion española del síndrome CDG, defectos congénitos de la glicosilación	http://webs.ono.com/aescdg	Associate member
Spain	Asociación Española Aniridia	www.aniridia.es	Full Member
Spain	Asociación Española de Afectados por Sarcoma	www.aeasarcomas.org	Full member
Spain	Asociación Española De Angioedema Familiar	www.angioedema-aedaf.org	Full Member
Spain	Asociación Española de Enfermos de Glucogenosis	www.glucogenosis.org	Full Member
Spain	Asociación Española de Enfermos de Pompe	www.asociaciondepompe.org	Associate member
Spain	Asociación Española de Enfermos y Familiares de la Enfermedad de Gaucher España	www.aeefegaucher.es	Full Member
Spain	Asociación Española de Esclerodermia	www.esclerodermia.com	Full Member
Spain	Asociación Española de Familiares y Enfermos de Wilson	www.enfermedaddewilson.org	Full Member
Spain	Asociación Española de Fibrodisplasia Osificante Progresiva	www.aefop-es.org	Full member
Spain	Asociación Española de Fiebre Mediterránea Familiar	http://fmf.org.es	Full member
Spain	Asociación Española de Ictiosis	www.ictiosis.org	Full member
Spain	Asociación Española de Mastocitosis y Enfermedades Relacionadas	www.mastocitosis.com	Full member
Spain	Asociación Española de Paraparesia Espástica Familiar Strümpell-Lorrain	www.aepfef.org	Full member
Spain	Asociación Española de Porfiria	www.porfiria.org	Full Member
Spain	Asociación Española de Raquitismo Hipofosfatémico y Osteomalacia	webaerho.wixsite.com/aerhyo	Associate member
Spain	Asociación Española de Síndrome De Poland	www.aesip.es	Full member
Spain	Asociación Española del Síndrome de Joubert	http://webs.ono.com/sindrome_joubert/	Full Member
Spain	Asociación Española Síndrome de Sjögren	www.aesjogren.org	Full Member
Spain	Asociación HHT España	www.asociacionhht.org	Full Member
Spain	Asociación Miradas que Hablan Duplicación Mecp2	www.duplicacionmecp2.es	Full member
Spain	Asociación Nacional Amigos de Arnold Chiari	www.chiari.biz	Full member
Spain	Asociación Nacional de Hipertensión Pulmonar	www.hipertensionpulmonar.es	Full member
Spain	Asociación Nacional Síndrome de Apert y otras Craneosinostosis Síndromicas	www.ansapert.org	Full Member
Spain	Asociación Síndrome de Angelman	www.angelman-asa.org	Full Member
Spain	Asociación Síndrome de Lowe de España	www.sindromelowe.es	Full member
Spain	Asociación Síndrome Lesch Nyhan España	www.asociacionlesch-nyhan.org.es	Full member
Spain	Asociación Stop Sanfilippo	www.stopsanfilippo.org	Associate member
Spain	Asociación Catalana de la Delecció 22Q	www.22q.cat	Full member
Spain	Asociación Catalana de Síndrome de Sjögren		Full member
Spain	Asociación d'Apràxia Ocular i Malalties Associades	apraxiaocular.blogspot.com	Associate member
Spain	Asociación Catalana de Enfermedades Neuromusculares	www.asemcatalunya.com	Full member

Spain	D'Genes Asociación de Enfermedades Raras de Murcia	http://www.dgenes.es/	Full member
Spain	Dravet Syndrome Foundation, Delegacion en Espana	www.dravetfoundation.eu	Associate member
Spain	Duchenne Parent Project España	www.duchenne-spain.org	Full member
Spain	European Network for Rare and Congenital Anaemias	www.enerca.org	Associate Member
Spain	FEDER - Federación Española de Enfermedades Raras	www.enfermedades-raras.org	Full Member
Spain	Federació Catalana de Malalties Minoritàries	www.fcmpf.entitatsbcn.net	Full member
Spain	Federación de Asociaciones de Retinosis Pigmentaria de España	www.retinosisfarpe.org	Full member
Spain	Federación de Ataxias de España	www.fedaes.org	Full Member
Spain	Federación Española de Enfermedades Neuromusculares	www.asem-esp.org	Full Member
Spain	Federación Española de Fibrosis Quística	http://www.fibrosis.org/	Full Member
Spain	Federación Española de Hemofilia	www.hemofilia.com	Full Member
Spain	Federación Española de Malformación de Chiari y patologías asociadas	www.femacpa.com	Associate member
Spain	Federacion Espanola de Padres con Ninos con Cancer	www.cancerinfantil.org	Full member
Spain	Federación Española del Síndrome X Frágil	www.xfragil.org	Full member
Spain	Fundación Andrés Marcio, niños contra la laminopatía	www.fundacionandresmarcio.org	Full member
Spain	Fundacion Menudos Corazones	www.menudoscrazones.org	Full member
Spain	Fundación Niemann-Pick de España	www.fnp.es	Full member
Spain	Fundación Síndrome 5p menos	www.fundacionsindrome5p.org	Full member
Spain	Fundación Síndrome de Moebius	www.moebius.org	Full Member
Spain	Fundacion Sindrome de West	www.sindromedewest.org	Full member
Spain	Fundación Síndrome Wolf Hirschhorn 4p-	www.4pmenos.org	Full member
Spain	hipertension pulmonar españa organizacion de pacientes - Hpe-org	www.hipertension-pulmonar.com	Associate member
Spain	Instituto de Investigación y Desarrollo social de Enfermedades poco Frecuentes	www.pocofrecuentes.org	Associate member
Spain	Miquel Valls Foundation (Fundacion Privada Catalana de Esclerosi Lateral Amiotrofica)	www.elacat.org	Associate member
Sweden	Agrenska	www.agrenska.se	Full Member
Sweden	Aorta Dissektion Föreningen Skandinavien	www.aortadissektion.com	Full member
Sweden	European Dysmelia Reference Information Centre	www.edric.eu	Full member
Sweden	Neuroförbundet / Swedish Association of persons with Neurological disabilities	http://neuroforbundet.se	Associate member
Sweden	Prader Willi Syndrome Association in Sweden	www.prader-willi.se	Full member
Sweden	Primär immunbrist organisationen	www.pio.nu	Full member
Sweden	Rare Diseases Sweden (Riksförbundet Sällsynta Diagnoser)	www.sallsyntadiagnoser.se	Full Member
Sweden	Svensk förening för Hypoparatyreodism	www.hypopara-nordic.org	Associate member

Sweden	Svenska Marfanföreningen	www.marfanforeningen.se/	Full Member
Sweden	Swedish Cystic Fibrosis Association	www.rfcf.se	Full Member
Sweden	Swedish EDS Association (EDS Riksförbund)	www.ehlers-danlos.se	Full Member
Sweden	Swedish MPS Society	www.mpsforeningen.se	Full member
Sweden	The Swedish Cooperative Body Of Organizations Of Disabled People	www.gbghso.se	Full Member
Sweden	Wilhelm Foundation	www.wilhelmfoundation.org	Full member
Switzerland	Association enfance et Maladies Orphelines	www.aemo.ch	Associate member
Switzerland	Association Suisse Romande Intervenant contre les Maladies neuro-Musculaires	www.asrimm.ch	Full Member
Switzerland	Blackswan Foundation	www.blackswanfoundation.ch	Associate member
Switzerland	Esperare	www.esperare.org	Associate member
Switzerland	FMF & AID Global Association	www.fmfandaid.org	Associate member
Switzerland	Fondation Sanfilippo Suisse	www.fondation-sanfilippo.org	Associate member
Switzerland	Foundation Orphanhealthcare	www.orphanhealthcare.com	Associate member
Switzerland	FRAXAS - Association X Fragile Suisse	www.fraxas.ch	Full Member
Switzerland	HAEi - Hereditary Angioedema International Association	http://www.haei.org	Associate member
Switzerland	HHT-Swiss	www.hhtswiss.org	Associate member
Switzerland	Leukemia Patient Advocates Foundation	www.cmladvocates.net	Associate member
Switzerland	MaRaVal - maladies rares valais - seltene krankheiten wallis	http://www.maraval.ch/	Associate member
Switzerland	Marfan Foundation Switzerland (Marfan Stiftung Schweiz)	www.marfan.ch	Full Member
Switzerland	Prader Willi Syndrom Vereinigung Schweiz	www.prader-willi.ch	Full Member
Switzerland	ProRaris	www.proraris.ch	Full member
Switzerland	Retina International	www.retina-international.org	Full member
Switzerland	Schweizerische Gesellschaft für Familiäre Formen der Hypercholesterinämie	www.sgfh.ch	Associate member
Switzerland	Schweizerische Gesellschaft für Porphyrie	www.porphyrria.ch	Full member
Switzerland	Selbsthilfe Ichthyose Schweiz	www.ichthyose.ch	Associate member
Switzerland	SMA Schweiz	www.sma-schweiz.ch	Associate member
Taiwan, Province Of China	Taiwan Foundation for Rare Disorders	www.tfrd.org.tw	Associate Member
The Former Yugoslav Republic of Macedonia	Life with Challenges	http://challenges.mk/?p=2288&lang=en	Full member
The Former Yugoslav Republic of Macedonia	National Alliance for Rare Diseases of R. Macedonia		Full member

The Former Yugoslav Republic of Macedonia	Save Liver Association of Patients with liver diseases	facebook/SLAPSave LiverAssociationforPatients	Full member
The Former Yugoslav Republic of Macedonia	Zdruzenie za Cisticna Fibroza (Macedonian CF Association)	www.cf.mk	Full member
Turkey	KifDER	www.kistikfibrozis.org.tr	Associate member
Turkey	Mukopolisakkaridoz ve Benzeri Lizozomal Depo Hastaliklari Dernegi	www.mpsturk.org	Associate member
Ukraine	Association of patients with pulmonaty hypertension	www.pha.org.ua	Full member
Ukraine	Charitable Foundation of Sister Dalila	http://poryatunok.info/uk/	Associate member
Ukraine	Kharkiv's Charitable Foundation - "Children with Spinal Muscular Atrophy"	www.csma.org.ua	Full Member
Ukraine	Non-governmental Organization "Rare Diseases of Ukraine"	http://rarediseases.org.ua/index.php/en/	Associate member
Ukraine	Ukrainian Association Crystal People	http://ostimperfecta.wix.com/oiua	Associate member
Ukraine	Ukrainian National charitable fund ZAPORUKA	www.zaporuka.com.ua	Associate member
Ukraine	Ukrainian Union of Patients' Organisations	www.patient.in.ua	Associate member
Ukraine	Ukranian Parent Project "Mio-Life"	miolife.org	Associate member
Ukraine	UPO-Ukrainian association of help for patients with CF	facebook.com/cvsticfibrosisua	Full member
United Kingdom of Great Britain and Northern Ireland	Advocacy for Neuroacanthocytosis Patients	www.naadvocacy.org	Associate member
United Kingdom of Great Britain and Northern Ireland	AKU Society	http://www.akusociety.org	Full member
United Kingdom of Great Britain and Northern Ireland	ALD LIFE	www.aldlife.org	Associate member
United Kingdom of Great Britain and Northern Ireland	Alstrom Syndrome Europe		Associate member
United Kingdom of Great Britain and Northern Ireland	Alstrom Syndrome UK	www.alstrom.org.uk	Full Member
United Kingdom of Great Britain and Northern Ireland	Amyloidosis Research Consortium UK		Associate member

United Kingdom of Great Britain and Northern Ireland	Ann Edgar Charitable Trust - Neuroendocrine Tumour Support	www.taect.scot	Full member
United Kingdom of Great Britain and Northern Ireland	Annabelle's Challenge	www.annabelleschallenge.org	Full member
United Kingdom of Great Britain and Northern Ireland	Association for Glycogen Storage Disease	www.agsd.org.uk	Full member
United Kingdom of Great Britain and Northern Ireland	Association for Multiple Endocrine Neoplasia Disorders	www.amend.org.uk	Full member
United Kingdom of Great Britain and Northern Ireland	Ataxia UK	www.ataxia.org.uk	Full member
United Kingdom of Great Britain and Northern Ireland	Batten Disease Family Association	http://www.bdfa-uk.org.uk/about-batten-disease	Full member
United Kingdom of Great Britain and Northern Ireland	Behcets Syndrome Society	www.behcets.org.uk	Full member
United Kingdom of Great Britain and Northern Ireland	Brittle Bone Society	www.brittlebone.org	Associate member
United Kingdom of Great Britain and Northern Ireland	Cambridge Rare Disease Network (CRDN)	www.camraredisease.com	Associate member
United Kingdom of Great Britain and Northern Ireland	Cancer 52	www.cancer52.org.uk	Associate member
United Kingdom of Great Britain and Northern Ireland	Cavernoma Alliance UK	www.cavernoma.org.uk	Full member
United Kingdom of Great Britain and Northern Ireland	Child Growth Foundation	www.childgrowthfoundation.org	Full member

United Kingdom of Great Britain and Northern Ireland	ChILD Lung Foundation	www.childlungfoundation.org	Associate member
United Kingdom of Great Britain and Northern Ireland	Children Living With Inherited Metabolic Diseases	www.climb.org.uk	Full Member
United Kingdom of Great Britain and Northern Ireland	Ciliopathy Alliance	www.ciliopathyalliance.org	Full member
United Kingdom of Great Britain and Northern Ireland	Contact a Family	www.cafamily.org.uk	Full Member
United Kingdom of Great Britain and Northern Ireland	Cystinosis Foundation of the UK	www.cystinosis.org.uk	Full member
United Kingdom of Great Britain and Northern Ireland	Dancing Eye Syndrome Support Trust	www.dancingeyes.org.uk	Full Member
United Kingdom of Great Britain and Northern Ireland	Degos Disease Support Network	www.degosdisease.com	Associate member
United Kingdom of Great Britain and Northern Ireland	Ectodermal Dysplasia Society	www.ectodermaldysplasia.org	Full Member
United Kingdom of Great Britain and Northern Ireland	European Gaucher Alliance	www.eurogaucher.org	Full member
United Kingdom of Great Britain and Northern Ireland	European Lung Foundation	www.european-lung-foundation.org/	Associate member
United Kingdom of Great Britain and Northern Ireland	European Myasthenia Gravis Association	www.eumga.eu	Associate member
United Kingdom of Great Britain and Northern Ireland	European Tuberous Sclerosis Complex Association	www.e-tsc.eu	Full Member
United Kingdom of Great Britain and Northern Ireland	Fabry International Network	www.fabrynetwork.org/	Associate member
United Kingdom of Great Britain and Northern Ireland	Fetal Anti Convulsant Syndrome Association		Associate member

United Kingdom of Great Britain and Northern Ireland	Findacure: The Fundaemental Diseases Partnership	www.findacure.org.uk	Associate member
United Kingdom of Great Britain and Northern Ireland	FOP Friends	www.fopfriends.com	Full member
United Kingdom of Great Britain and Northern Ireland	Gauchers Association UK	www.gaucher.org.uk	Full Member
United Kingdom of Great Britain and Northern Ireland	Genetic Alliance UK	www.geneticalliance.org.uk	Full Member
United Kingdom of Great Britain and Northern Ireland	International Brain Tumour Alliance	www.theibta.org	Associate member
United Kingdom of Great Britain and Northern Ireland	International Niemann-Pick Disease Alliance	www.inpda.org	Full member
United Kingdom of Great Britain and Northern Ireland	IPOPI - International Patient Organization for Primary Immunodeficiencies	www.ipopi.org	Full Member
United Kingdom of Great Britain and Northern Ireland	Joining Jack	www.joiningjack.org	Full member
United Kingdom of Great Britain and Northern Ireland	Leber's Hereditary Optic Neuropathy Society	www.lhonsociety.org	Full member
United Kingdom of Great Britain and Northern Ireland	Lymphangiomatosis & Gorham Disease Alliance Europe	www.lgda.eu	Full member
United Kingdom of Great Britain and Northern Ireland	Max Appeal	www.maxappeal.org.uk	Full member
United Kingdom of Great Britain and Northern Ireland	MEBO Research	www.meboresearch.org	Associate member

United Kingdom of Great Britain and Northern Ireland	MPS Society	www.mpssociety.co.uk	Full Member
United Kingdom of Great Britain and Northern Ireland	myaware	www.myaware.org/	Full member
United Kingdom of Great Britain and Northern Ireland	Myotubular Trust	www.myotubulartrust.org	Full member
United Kingdom of Great Britain and Northern Ireland	Newlife Foundation for Disabled Children	www.bdfnewlife.co.uk	Full Member
United Kingdom of Great Britain and Northern Ireland	Niemann-Pick Disease Group UK	www.niemann-pick.org.uk	Full Member
United Kingdom of Great Britain and Northern Ireland	Northern Ireland Rare Disease Partnership	www.nirdp.org.uk	Full member
United Kingdom of Great Britain and Northern Ireland	One in a million - Pseudomyxoma Survivor	www.pseudomyxomasurvivor.co.uk	Associate member
United Kingdom of Great Britain and Northern Ireland	Organisation for Anti-Convulsant Syndrome	www.oacscharity.org	Full member
United Kingdom of Great Britain and Northern Ireland	Pitt Hopkins UK	http://pitthopkins.org.uk/	Full member
United Kingdom of Great Britain and Northern Ireland	Polycystic Kidney Disease Charity (PKDC)	www.pkdcharity.org.uk	Full member

United Kingdom of Great Britain and Northern Ireland	Prader Willi Syndrome Association UK	www.pwsa.co.uk	Full Member
United Kingdom of Great Britain and Northern Ireland	PSC Support	www.pscsupport.org.uk	Full member
United Kingdom of Great Britain and Northern Ireland	PTEN Research Foundation	www.ptenresearch.org	Associate member
United Kingdom of Great Britain and Northern Ireland	Rare Autoinflammatory Conditions Community - UK	www.raccuk.com	Associate member
United Kingdom of Great Britain and Northern Ireland	Rare Diseases UK	www.raredisease.org.uk	Associate member
United Kingdom of Great Britain and Northern Ireland	Ring 20 Research and Support UK CIO	http://ring20researchsupport.co.uk/	Associate member
United Kingdom of Great Britain and Northern Ireland	Spinal Muscular Atrophy Support UK	www.smasupportuk.org.uk	Full Member
United Kingdom of Great Britain and Northern Ireland	Stiff Person Support Group	www.smssupportgroup.co.uk	Full Member
United Kingdom of Great Britain and Northern Ireland	Sturge-Weber UK	www.sturgeweber.org.uk	Full Member
United Kingdom of Great Britain and Northern Ireland	The AADC Research Trust Children's Charity	www.aadcresearch.org	Full member
United Kingdom of Great Britain and Northern Ireland	The Aarskog Foundation	www.aarskogsyndrome.foundation.co.uk	Associate member

United Kingdom of Great Britain and Northern Ireland	The Chromosome 18 Registry and Research Society (Europe)	www.chromosome18eur.org	Associate member
United Kingdom of Great Britain and Northern Ireland	The Cure & Action for Tay-Sachs (CATS) Foundation	www.cats-foundation.org	Full member
United Kingdom of Great Britain and Northern Ireland	The Ehlers-Danlos Society	http://ehlers-danlos.com/	Full member
United Kingdom of Great Britain and Northern Ireland	The Fragile X Society	www.fragilex.org.uk/	Full member
United Kingdom of Great Britain and Northern Ireland	The Maddi Foundation	http://themaddifoundation.com/	Associate member
United Kingdom of Great Britain and Northern Ireland	The PBC Foundation (UK) Ltd	www.pbcfoundation.org.uk	Associate member
United Kingdom of Great Britain and Northern Ireland	The Ultra Rare Diseases, Disorders & Disabilities Foundation	www.ultrarare-disease.uk	Associate member
United Kingdom of Great Britain and Northern Ireland	Tuberous Sclerosis Association	www.tuberous-sclerosis.org	Full Member
United Kingdom of Great Britain and Northern Ireland	UK Mastocytosis Support Group	www.ukmasto.co.uk	Full member
United Kingdom of Great Britain and Northern Ireland	Unique - The Rare Chromosome Disorder Support Group	www.rarechromo.org	Full Member

United Kingdom of Great Britain and Northern Ireland	United Kingdom Thalassaemia Society	www.ukts.org	Full member
United Kingdom of Great Britain and Northern Ireland	Uveitis Information Group	www.uveitis.net	Full member
United Kingdom of Great Britain and Northern Ireland	Vasculitis UK (The Vasculitis Trust)	www.vasculitis.org.uk	Full member
United States	Alagille Syndrome Alliance	www.alagille.org	Associate member
United States	Alstrom Syndrome International	www.alstrom.org	Associate member
United States	APS Foundation of America, Inc (APSFA)	www.apsfa.org	Associate member
United States	Children's Tumor Foundation	www.ctf.org	Associate member
United States	Chordoma Foundation	www.chordoma.org	Associate member
United States	Cure PSP	www.curepsp.org	Associate member
United States	Cystinosis Foundation	www.cystinosisfoundation.org	Associate member
United States	FMD Chat	http://fmdchat.blogspot.fr/	Associate member
United States	International FOXG1 Foundation	foxg1.org	Associate member
United States	International Pemphigus & Pemphigoid Foundation	www.pemphigus.org	Associate member
United States	International Waldenstrom's Macroglobulinemia Foundation	www.iwmf.com	Associate member
United States	MCT8-AHDS Foundation Inc.	www.mct8.info	Associate member
United States	Neuromuscular Disease Foundation	CureHIBM.org	Associate member
United States	NORD National Organization For Rare Disorders	www.rarediseases.org	Associate Member
United States	NTM Info & Research	www.ntminfo.org	Associate member
United States	PTEN Hamartoma Tumor Syndrome Foundation	www.ptenfoundation.org	Associate member
United States	PURA Syndrome Foundation	www.purasyndrome.org	Associate member
United States	The Cushing Support & Research Foundation	www.csrf.net	Associate member
United States	The Oxalosis & Hyperoxaluria Foundation	www.ohf.org	Associate member
Uruguay	Asociacion Acondroplasia Uruguay	www.acondroplasiauruguay.org	Associate member
Venezuela	Fundación Fura	http://fundacion-fura.mozello.com (en construcción)	Associate member