

## EURORDIS Member Associations - October 2017



Country	Name	Website	Membership
Albania	Shoqata e Semundjeve te Rralla - Rare Disease Association	<a href="http://www.rda-al.com">www.rda-al.com</a>	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	<a href="http://www.fundaciongeiser.org">www.fundaciongeiser.org</a>	Associate Member
Armenia	Doctors and Children Health Care		Associate Member
Armenia	Neurohereditary Diseases Charity Association		Associate Member
Australia	Cystic Fibrosis Australia	<a href="http://www.cysticfibrosis.org.au">www.cysticfibrosis.org.au</a>	Associate Member
Australia	Genetic Alliance Australia	<a href="http://www.geneticalliance.org.au">www.geneticalliance.org.au</a>	Associate Member
Australia	Rare Voices Australia	<a href="http://www.rarevoices.org.au">www.rarevoices.org.au</a>	Associate Member
Austria	Angelman Verein Österreich	<a href="http://www.angelman.at">www.angelman.at</a>	Full Member
Austria	Debra International	<a href="http://www.debra-international.org">www.debra-international.org</a>	Full Member
Austria	Hand in Hand gegen Tay-Sachs und Sandhoff	<a href="http://www.tay-sachs.net">www.tay-sachs.net</a>	Associate Member
Austria	ICA Österreich	<a href="http://www.ica-austria.at">www.ica-austria.at</a>	Full Member
Austria	NF Kinder – Verein zur Förderung der Neurofibromatoseforschung Österreich	<a href="http://www.nfkinder.at">www.nfkinder.at</a>	Associate Member
Austria	Pro Rare Austria, Allianz für seltenen Erkrankungen	<a href="http://www.prorare-austria.org">www.prorare-austria.org</a>	Associate Member
Austria	Pulmonary Hypertension Association Europe	<a href="http://www.phaeurope.org">www.phaeurope.org</a>	Associate Member
Austria	Selbsthilfegruppe Lungenhochdruck - Austrian Ph Patient Group	<a href="http://www.lungenhochdruck.at">www.lungenhochdruck.at</a>	Full Member
Austria	Usher Deafblind Forum Austria	<a href="http://www.usher-taubblind.at">www.usher-taubblind.at</a>	Associate Member
Belarus	Belarussian Organization of patients with MPS and other rare genetic disorders	<a href="http://www.mpsociety.by">http://www.mpsociety.by</a>	Full Member
Belgium	22q11 Europe	<a href="https://www.facebook.com/22q11europeancongress/">https://www.facebook.com/22q11europeancongress/</a>	Associate Member
Belgium	Alpha-1 Plus asbl	<a href="http://www.alpha1plus.be/">www.alpha1plus.be/</a>	Associate Member
Belgium	ALS Liga België	<a href="http://www.alsliga.be">www.alsliga.be</a>	Full Member
Belgium	Association Belge du Syndrome de Marfan Asbl	<a href="http://www.marfan.be">www.marfan.be</a>	Full Member
Belgium	Association De Patients Souffrant d'Hypertension Artérielle Pulmonaire en Belgique	<a href="http://test.ph-vzw.be/fr_FR/">http://test.ph-vzw.be/fr_FR/</a>	Full Member
Belgium	Association pour l'information et la recherche sur les maladies rénales génétiques	<a href="http://www.airg-belgique.org">http://www.airg-belgique.org</a>	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.euro-ataxia.eu	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.devidts.com/ichthyosis	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	Sobrevivre vzw	sites.google.com/site/sobrevivrevzw/welkom/presentation	Associate Member
Belgium	Vascular Anomaly Patient Association	www.vascapa.org	Full Member
Belgium	Vlaams Patiëntenplatform vzw	www.vlaamspatientenplatform.be	Associate Member
Belgium	Vlaamse Vereniging Neuromusculaire Aandoeningen Vzw (NEMA)	www.nema.be	Full 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 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	<a href="http://rare-bg.com/">http://rare-bg.com/</a>	Associate Member
Bulgaria	National Association for Child Support Congenital Hypothyroidism		Associate Member
Bulgaria	National Association of the Patients with Growth Hormone Deficiency	<a href="https://www.facebook.com/Национална-Асоциация-на-пациентите-с-дефицит-на-растежния-хормон-1543573779219269/?fref=hovercard">https://www.facebook.com/Национална-Асоциация-на-пациентите-с-дефицит-на-растежния-хормон-1543573779219269/?fref=hovercard</a>	Full Member
Bulgaria	National Gaucher Organization	<a href="http://gaucher-bg.org/">http://gaucher-bg.org/</a>	Associate Member
Bulgaria	National Sclerosis Association	<a href="http://nasbg.eu">http://nasbg.eu</a>	Associate Member
Bulgaria	National syringomyelia association		Full Member
Bulgaria	PHA Bulgaria	<a href="http://www.phabulgaria.eu">www.phabulgaria.eu</a>	Full Member
Bulgaria	The Bulgarian Society of Patients with Pulmonary Hypertension	<a href="http://www.bspph.net">www.bspph.net</a>	Full Member
Burkina Faso	Fondation Internationale Tierno et Mariam	<a href="http://www.fitima.org">www.fitima.org</a>	Associate Member
Canada	Canadian Organization For Rare Disorders	<a href="http://www.raredisorders.ca">www.raredisorders.ca</a>	Associate Member
Canada	Lymphoma Coalition	<a href="http://www.lymphomacoalition.org/">http://www.lymphomacoalition.org/</a>	Associate Member
Canada	PVNH support & Awareness	<a href="http://www.pvnhsupport.com">www.pvnhsupport.com</a>	Associate Member
China	Chinese Organization for Rare Disorders	<a href="http://www.hanjianbing.org">www.hanjianbing.org</a>	Associate Member
Colombia	Asociación Colombiana de Pacientes con Enfermedades de Depósito Lisosomal	<a href="http://www.acopel.org">http://www.acopel.org</a>	Associate Member
Croatia	Debra Croatia	<a href="http://www.debra-croatia.com">www.debra-croatia.com</a>	Full Member
Croatia	Rare Diseases Croatia	<a href="http://www.rijetke-bolesti.hr">www.rijetke-bolesti.hr</a>	Full Member
Cyprus	Association of Patients & Friends of IMD "Aspida Zois"	<a href="http://www.aspidazois.com">www.aspidazois.com</a>	Full Member
Cyprus	Cyprus Alliance for Rare Disorders	<a href="http://raredisorderscyprus.com">http://raredisorderscyprus.com</a>	Full Member
Cyprus	Cyprus Primary Immunodeficiency Association and Friends		Full Member
Cyprus	Pancyprian Association for Rare Genetic Diseases "Unique Smiles"	<a href="http://www.monadikaxamogela.com">www.monadikaxamogela.com</a>	Full Member
Cyprus	Thalassaemia International Federation (TIF)	<a href="http://www.thalassaemia.org.cy">www.thalassaemia.org.cy</a>	Full Member
Czech Republic	Czech Association of Marfan Syndrome	<a href="http://www.marfanuvsyndrom.websnadno.cz">www.marfanuvsyndrom.websnadno.cz</a>	Associate Member
Czech Republic	Czech Huntington Association	<a href="http://www.huntington.cz">www.huntington.cz</a>	Associate Member
Czech Republic	Czech National Association for Rare Diseases (Ceska asociace pro vzacna onemocneni)	<a href="http://www.vzacna-onemocneni.cz">www.vzacna-onemocneni.cz</a>	Full Member
Czech Republic	Klub Nemocnych Cystickou Fibrozou	<a href="http://www.cfklub.cz">www.cfklub.cz</a>	Full Member
Czech Republic	META, Association of Patients with Lysosomal Storage Diseases	<a href="http://www.sdruzenimeta.cz">www.sdruzenimeta.cz</a>	Full Member
Czech Republic	Narodni sdruzeni PKU a jinych DMP (Czech PKU Association)	<a href="http://www.nspku.cz">www.nspku.cz</a>	Full Member
Denmark	22q11 Danmark	<a href="http://www.22q11.dk">http://www.22q11.dk</a>	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 Foreningen i Danmark	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	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 Association of People with Physical Disabilities	www.invalidiliitto.fi	Full Member
Finland	Finnish Central Organisation for Skin Patients	http://www.iholiitto.fi	Full Member
Finland	Finnish Neuro Society	www.ms-liitto.fi	Full Member
Finland	HARSO-Rare Disease Alliance Finland	www.harso.fi	Associate Member
Finland	Harvinaiset Verkosto - Finnish Network for Rare Diseases	www.harvinaiset.fi	Associate Member
Finland	Inclusion Finland KVTL	www.kvtl.fi	Full Member
Finland	Rinnekoti Foundation, Norio Centre	www.rinnekoti.fi	Associate Member
France	AFMKT-France	www.associationkystedetarlov.com	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	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	<a href="http://www.association-ammi.org">www.association-ammi.org</a>	Full Member
France	Association Craniopharyngiome Solidarité	<a href="http://www.cranio.fr">www.cranio.fr</a>	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	<a href="http://www.fondation-denisepicard.org">www.fondation-denisepicard.org</a>	Associate Member
France	Association de Soutien et d'Information à la Leucémie Lymphoïde Chronique et la maladie de Waldenström	<a href="http://www.sillc-asso.org">www.sillc-asso.org</a>	Full Member
France	Association des Amis d'Anne-Lorène - Syndrome d'Aicardi	<a href="http://www.aicardi.info">www.aicardi.info</a>	Full Member
France	Association Des Groupes Amitié Turner	<a href="http://www.agat-turner.org">www.agat-turner.org</a>	Full Member
France	Association des Malades du Syndrome de Mccune-Albright	<a href="http://www.assymcal.org">www.assymcal.org</a>	Full Member
France	Association des Malades d'un Syndrome Néphrotique	<a href="http://amsn.ambitionrecherche.fr/">http://amsn.ambitionrecherche.fr/</a>	Full Member
France	Association des Malades souffrant d'Angio Oedème par déficit en C1 Inhibiteur	<a href="http://www.amsao.fr">www.amsao.fr</a>	Full Member
France	Association des Pancréatites Chroniques Héritaires	<a href="http://www.association-apch.org">www.association-apch.org</a>	Full Member
France	Association des Patients de La Maladie de Fabry	<a href="http://www.apmf-fabry.org">www.apmf-fabry.org</a>	Associate Member
France	Association des Personnes Concernées par le Tremblement Essentiel	<a href="http://www.apt.es.org">www.apt.es.org</a>	Associate Member
France	Association des POIC	<a href="http://www.association-poic.fr/">http://www.association-poic.fr/</a>	Full Member
France	Association du Locked-In Syndrome	<a href="http://www.alis-asso.fr">www.alis-asso.fr</a>	Full Member
France	Association du Naevus Géant Congénital	<a href="http://naevus.fr">naevus.fr</a>	Full Member
France	Association Française contre l'Amylose	<a href="http://www.amylose.asso.fr">www.amylose.asso.fr</a>	Full Member
France	Association Française contre les Myopathies	<a href="http://www.afm-France.org">www.afm-France.org</a>	Full Member
France	Association Française de la Fièvre Méditerranéenne Familiale	<a href="https://www.affmf.com/">https://www.affmf.com/</a>	Full Member
France	Association Française de la Maladie de Fanconi	<a href="http://www.fanconi.com">www.fanconi.com</a>	Full Member
France	Association Française de l'Ataxie de Friedreich	<a href="http://www.afaf.asso.fr/">www.afaf.asso.fr/</a>	Full Member
France	Association Française de l'Osteodystrophie Héritaire d'Albright	<a href="http://www.afoha.org">www.afoha.org</a>	Full Member
France	Association Française de l'Ostéogénèse Imparfait	<a href="http://www.aoi.asso.fr">www.aoi.asso.fr</a>	Full Member
France	Association Française de Narcolepsie-Cataplexie et Hypersomnie	<a href="http://www.anc-narcolepsie.com">www.anc-narcolepsie.com</a>	Full Member
France	Association Française des Dysplasies Ectodermiques	<a href="http://www.afde.net">www.afde.net</a>	Full Member
France	Association Française des Hémophiles	<a href="http://www.afh.asso.fr">www.afh.asso.fr</a>	Full Member
France	Association Française des Malades Atteints de Porphyries	<a href="http://www.porphyrries-patients.org">www.porphyrries-patients.org</a>	Associate Member
France	Association Française des Maladies Héritaires du Rythme Cardiaque	<a href="http://www.afmhrc.org">www.afmhrc.org</a>	Full Member
France	Association Française des Patients en Auto-Traitement	<a href="http://www.afpat.fr">www.afpat.fr</a>	Associate Member
France	Association Française Des Syndromes d'Ehlers-Danlos	<a href="http://www.afsed.com">www.afsed.com</a>	Full Member

France	Association Française du Gougerot-Sjögren	<a href="http://www.afgs-syndromes-secs.org">www.afgs-syndromes-secs.org</a>	Full Member
France	Association Française du Lupus et autres maladies Auto-Immunes	<a href="http://www.lupusplus.com">www.lupusplus.com</a>	Full Member
France	Association Française du Syndrome de Cornelia de Lange	<a href="http://afscdl.fr">http://afscdl.fr</a>	Full Member
France	Association Française du Syndrome de Rett	<a href="http://www.afsr.net">www.afsr.net</a>	Full Member
France	Association Française du Syndrome d'Ondine	<a href="http://www.afsondine.org/">www.afsondine.org/</a>	Full Member
France	Association Française du Syndrome Phelan-Mcdermid	<a href="http://22q13.fr">http://22q13.fr</a>	Full Member
France	Association Française Lesch-Nyhan Action	<a href="http://www.lesch-nyhan-action.org">www.lesch-nyhan-action.org</a>	Full Member
France	Association Française pour le Syndrome de Gilles de la Tourette	<a href="http://www.france-tourette.org">www.france-tourette.org</a>	Full Member
France	Association France Vascularites	<a href="http://www.association-vascularites.org">www.association-vascularites.org</a>	Full Member
France	Association François Aupetit	<a href="http://www.afa.asso.fr">www.afa.asso.fr</a>	Associate Member
France	Association Francophone contre la Polychondrite Chronique A	<a href="http://www.afpca.fr">www.afpca.fr</a>	Associate Member
France	Association Francophone des Glycogénoses	<a href="http://www.glycogenoses.org">www.glycogenoses.org</a>	Full Member
France	Association Francophone du Syndrome d'Angelman	<a href="http://www.angelman-afsa.org">www.angelman-afsa.org</a>	Full Member
France	Association Hemochromatose France	<a href="http://www.hemochromatose.fr">www.hemochromatose.fr</a>	Associate Member
France	Association Histiocytose France	<a href="http://www.histiocytose.org">www.histiocytose.org</a>	Full Member
France	Association Huntington France	<a href="http://www.huntington.fr">www.huntington.fr</a>	Full Member
France	Association Hypoparathyroidisme France	<a href="http://www.hypopara.fr">www.hypopara.fr</a>	Full Member
France	Association Ichtyose France	<a href="http://www.anips.net">www.anips.net</a>	Full Member
France	Association internationale maladies kystes Tarlov	<a href="http://www.aimktarlov.org">http://www.aimktarlov.org</a>	Associate Member
France	Asociation ISIS	<a href="http://www.isis-asso.com">www.isis-asso.com</a>	Full Member
France	Association Kourir	<a href="http://www.kourir.org">www.kourir.org</a>	Full Member
France	Association Maladies Foie Enfants	<a href="http://www.asprehp.org">www.asprehp.org</a>	Full Member
France	Association Marfans	<a href="http://www.assomarfans.fr">www.assomarfans.fr</a>	Full Member
France	Association Médicalistes	<a href="http://www.medicalistes.org">www.medicalistes.org</a>	Associate Member
France	Association Microphthalmie France	<a href="http://asso-microphthalmie.org">http://asso-microphthalmie.org</a>	Full Member
France	Association Naevus 2000 France Europe	<a href="http://www.naevus2000franceeurope.org">www.naevus2000franceeurope.org</a>	Full Member
France	Association Nationale des Cardiaques Congénitaux	<a href="http://www.ancc.asso.fr">www.ancc.asso.fr</a>	Full Member
France	Association Nationale du Syndrome X Fragile "Le Goëland"	<a href="http://www.xfra.org">www.xfra.org</a>	Full Member
France	Association Neurofibromatoses & Recklinghausen	<a href="http://www.anrfrance.fr">www.anrfrance.fr</a>	Full Member
France	Association Ollier Maffucci Europe	<a href="http://www.olliermaffucci-asso.fr">www.olliermaffucci-asso.fr</a>	Full Member
France	Association Pemphigus – Pemphigoïdes France	<a href="http://www.pemphigus.asso.fr">www.pemphigus.asso.fr</a>	Full Member
France	Association pour la Lutte contre les maladies Inflammatoires du foie et des voies Biliaires	<a href="http://www.albi-france.org">www.albi-france.org</a>	Full Member
France	Association Pour Aider et Informer Les Syringomyéliques Européens Réunis	<a href="http://www.apaiser.asso.fr">www.apaiser.asso.fr</a>	Full Member
France	Association pour la Lutte contre l'Alcaptonurie	<a href="http://www.alcap.fr">www.alcap.fr</a>	Full Member
France	Association pour la Recherche sur la Sclérose Latérale Amyotrophique	<a href="http://www.arsla.org">www.arsla.org</a>	Associate Member

France	Association pour l'aide aux personnes concernées par les maladies rares Muckle Wells Syndrome et CINCA	<a href="http://www.amws-cinca.eu">www.amws-cinca.eu</a>	Full Member
France	Association pour l'information et la prévention de la Drépanocytose	<a href="http://www.apipd.fr">www.apipd.fr</a>	Full Member
France	Association pour l'information et la Recherche sur le Syndrome de SAPHO	<a href="http://www.airss-sapho.org">www.airss-sapho.org</a>	Full Member
France	Association pour l'information et la Recherche sur les Maladies Rénales Génétiques	<a href="http://www.airg-france.org">www.airg-france.org</a>	Full Member
France	Association Sans Diagnostic et Unique	<a href="http://www.asdu.fr">www.asdu.fr</a>	Associate Member
France	Association Sclérose Tubéreuse De Bourneville	<a href="http://www.astb.asso.fr">www.astb.asso.fr</a>	Full Member
France	Association Sos Desmoïde	<a href="http://www.sos-desmoide.asso.fr">www.sos-desmoide.asso.fr</a>	Full Member
France	Association Spina Bifida et Handicaps Associés	<a href="http://www.spina-bifida.org">www.spina-bifida.org</a>	Associate Member
France	Association Strümpell-Lorrain	<a href="http://www.asl-hsp-france.org">www.asl-hsp-france.org</a>	Full Member
France	Association Surrénales	<a href="http://www.surrenales.com">www.surrenales.com</a>	Full Member
France	Association Syndrome de Kleine-Levin	<a href="http://kls-france.org">kls-france.org</a>	Full Member
France	Association Syndrome de ROKITANSKY - MRKH	<a href="http://www.asso-mrkh.org">www.asso-mrkh.org</a>	Full Member
France	Association Thera Wanka	<a href="http://association-thera-wanka.org">http://association-thera-wanka.org</a>	Associate Member
France	Charcot-Marie-Tooth France	<a href="http://www.cmt-france.org">www.cmt-france.org</a>	Full Member
France	Cutis Laxa Internationale	<a href="http://www.cutislaxa.org">www.cutislaxa.org</a>	Full Member
France	Debra France	<a href="http://www.debra.fr">www.debra.fr</a>	Full Member
France	Dravet Syndrome European Federation	<a href="http://www.dravet.eu">www.dravet.eu</a>	Associate Member
France	Enfants de la Lune Association pour le Xeroderma Pigmentosum	<a href="http://www.enfantsdelalune.org">www.enfantsdelalune.org</a>	Full Member
France	European Federation Lesch-Nyhan Disease	<a href="http://www.LNDE.org">www.LNDE.org</a>	Associate Member
France	EUROPEAN FEDERATION OF ASSOCIATIONS OF PATIENTS WITH HAEMOCHROMATOSIS	<a href="http://efaph.eu/">http://efaph.eu/</a>	Full Member
France	Fédération des Malades Drépanocytaires et Thalassémiques SOS Globi	<a href="http://www.sosglobiparis.fr">www.sosglobiparis.fr</a>	Full Member
France	Federation Euro-HSP	<a href="http://www.eurohsp.eu">www.eurohsp.eu</a>	Full Member
France	FITIMA Europe - Fondation International Tierno et Mariam	<a href="http://www.fitima.org">www.fitima.org</a>	Full Member
France	FOP France	<a href="http://www.fopfrance.fr">www.fopfrance.fr</a>	Full Member
France	France Lymphangiomeiomyomatose (FLAM)	<a href="http://www.francelam.org">www.francelam.org</a>	Full Member
France	France Lymphome Espoir	<a href="http://www.francelymphomeespoir.fr">www.francelymphomeespoir.fr</a>	Full Member
France	Génération 22	<a href="http://www.generation22.fr">www.generation22.fr</a>	Full Member
France	Genespoir: Association Française des Albinismes	<a href="http://www.genespoir.org">http://www.genespoir.org</a>	Full Member
France	GENIRIS	<a href="http://associationgeniris.free.fr/">http://associationgeniris.free.fr/</a>	Full Member
France	HTAP France	<a href="http://www.htapfrance.com">www.htapfrance.com</a>	Full Member
France	Hypophosphatasie Europe	<a href="http://www.hypophosphatasie.com">www.hypophosphatasie.com</a>	Full Member
France	Incontinentia Pigmenti France	<a href="http://incontinentia-pigmenti.fr/">http://incontinentia-pigmenti.fr/</a>	Full Member
France	Inflam'œil	<a href="http://www.inflamoeil.org">www.inflamoeil.org</a>	Full Member

France	Les Enfants du Jardin	<a href="http://www.lesenfantsdujardin.fr/">http://www.lesenfantsdujardin.fr/</a>	Full Member
France	Les petits bourdons	<a href="http://www.lespetitsbourdons.org">www.lespetitsbourdons.org</a>	Associate Member
France	Ligue contre la Cardiomyopathie	<a href="http://www.ligue-cardiomyopathie.com/">http://www.ligue-cardiomyopathie.com/</a>	Associate Member
France	Ligue Nationale Contre Le Cancer	<a href="http://www.ligue-cancer.net">www.ligue-cancer.net</a>	Full Member
France	Lupus France	<a href="http://www.lupusfrance.com/">www.lupusfrance.com/</a>	Full Member
France	Mosaïques - Association des "X Fragile"	<a href="http://www.xfragile.org">www.xfragile.org</a>	Full Member
France	Naevus Global	<a href="http://www.naevusglobal.org">www.naevusglobal.org</a>	Associate Member
France	Polyposes Familiales - Aptepf	<a href="http://aptepf.free.fr/">http://aptepf.free.fr/</a>	Full Member
France	Prader Willi France	<a href="http://www.prader-willi.fr">www.prader-willi.fr</a>	Full Member
France	Retina France	<a href="http://www.retina.fr">www.retina.fr</a>	Full Member
France	Sanfilippo Sud	<a href="http://sanfilipposud.org/">http://sanfilipposud.org/</a>	Full Member
France	Solidarité Handicap autour des maladies rares	<a href="http://www.solhand-maladiesrares.org">www.solhand-maladiesrares.org</a>	Full Member
France	Syndrome De Moebius France	<a href="http://www.moebius-france.org">www.moebius-france.org</a>	Full Member
France	Union Huntington Espoir	<a href="http://www.huntington.asso.fr">www.huntington.asso.fr</a>	Full Member
France	Union Nationale des Associations Parents et Amis Personnes Handicapées Mentales	<a href="http://www.unapei.org">www.unapei.org</a>	Associate Member
France	Union Nationale des Syndromes d'Ehlers-Danlos	<a href="http://www.unsed.org">http://www.unsed.org</a>	Full Member
France	Vaincre la Mucoviscidose	<a href="http://www.vaincrelamuco.org">www.vaincrelamuco.org</a>	Full Member
France	Vaincre la Papillomatose Respiratoire Récurrente	<a href="http://www.vaincreprrr.fr">www.vaincreprrr.fr</a>	Full Member
France	Vaincre les Maladies Lysosomales	<a href="http://www.vml-asso.org">www.vml-asso.org</a>	Full Member
France	Valentin - Association des porteurs d'anomalies chromosomiques	<a href="http://www.valentin-apac.org">www.valentin-apac.org</a>	Full Member
France	VHL France	<a href="http://www.vhlfrance.org">www.vhlfrance.org</a>	Full Member
France	Xtraordinaire	<a href="http://www.xtraordinaire.org">www.xtraordinaire.org</a>	Full Member
Georgia	Georgian Foundation for Genetic and Rare Diseases		Associate Member
Germany	ACHSE Allianz Chronischer Seltener Erkrankungen e.V.	<a href="http://www.achse-online.de">www.achse-online.de</a>	Full Member
Germany	AHC-Deutschland eV	<a href="http://www.ahckids.de">www.ahckids.de</a>	Full Member
Germany	Aktion Benni & Co e.V.	<a href="http://www.benniundco.de">www.benniundco.de</a>	Full Member
Germany	Alpha 1 Netzwerk eV	<a href="http://www.alpha1-netzwerk.de">www.alpha1-netzwerk.de</a>	Full Member
Germany	BSHV für Kinder, Jugendliche und Erwachsene mit seltenen, chronischen Skeletterkrankungen e.V.	<a href="http://bshv-seltene-skelett-erkrankungen.com">bshv-seltene-skelett-erkrankungen.com</a>	Full Member
Germany	Bundesverband der Clusterkopfschmerzen-Selbsthilfe-Gruppen	<a href="http://www.clusterkopf.de">www.clusterkopf.de</a>	Full Member
Germany	Bundesverband für Angeborene Gefäßfehlbildungen e.V.	<a href="http://www.angiodyplasie.de">www.angiodyplasie.de</a>	Full Member
Germany	Bundesverband Kleinwüchsige Menschen und ihre Familien e.V.	<a href="http://www.bkmf.de">www.bkmf.de</a>	Full Member
Germany	Bundesverband Poliomyelitis eV	<a href="http://polio-selbsthilfe.de/willkommen">polio-selbsthilfe.de/willkommen</a>	Full Member
Germany	Charge Syndrom eV	<a href="http://www.charge-syndrom.de">www.charge-syndrom.de</a>	Full Member
Germany	Cystic Fibrosis Europe	<a href="http://www.cfww.org/cfe/">www.cfww.org/cfe/</a>	Full Member



Germany	Cystinose Selbsthilfe e.V.	www.leben-eben.com	Full Member
Germany	Deutsche Ehlers-Danlos-Initiative	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	www.ichthyose.eu	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.angioedem.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	Mastozytose Initiative Selbsthilfenetzwerk	www.mastozytose.com	Associate Member
Germany	Morbus-Osler Selbsthilfe	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	NCL-Gruppe Deutschland	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	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	www.ichthyose.de	Full Member
Germany	Selbsthilfegruppe Ektodermale Dysplasie e.V.	www.ektodermale-dysplasie.de	Full Member
Germany	Selbsthilfegruppe für PXE - Erkrankte Deutschlands	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-sh.de	Full Member
Germany	SMA Europe	www.sma-europe.eu	Full Member
Germany	Sos-desmoid e.V.	www.sos-desmoid.de	Full Member
Germany	Stiff-Person-Syndrom Selbsthilfe 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	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	Full 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		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	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 Immunhiányos Betegek Egyesülete	www.pibe.hu	Full Member
Hungary	Rare Diseases Hungary	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	Einstök Börn - 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.skbi.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	Alpha One Foundation	www.alpha1.ie	Full Member
Ireland	Ataxia Ireland	http://ataxia.ie/	Full Member
Ireland	Barretstown Serious Fun	www.barretstown.org	Associate Member
Ireland	Cystinosis Ireland	cystinosis.ie	Full Member
Ireland	Fighting Blindness	www.fightingblindness.ie	Full Member
Ireland	Friedreich's Ataxia Research Alliance	www.farairland.ie	Full Member
Ireland	Genetic and Rare Disorders Organisation (GRDO)	www.grdo.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	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	<a href="http://fragilexireland.org">http://fragilexireland.org</a>	Full Member
Israel	Israel Adult Polyglucosan Body Disease		Associate Member
Italy	ABC Associazione Bambini Cri du Chat	<a href="http://www.criduchat.it">www.criduchat.it</a>	Full Member
Italy	Acondroplasia - Insieme per crescere - Onlus	<a href="http://www.acondroplasia-insiemepercrescere.it">www.acondroplasia-insiemepercrescere.it</a>	Full Member
Italy	AIBWS Onlus	<a href="http://www.aibws.org">www.aibws.org</a>	Full Member
Italy	Amici della Porfiria - San Pio da Pietrelcina Onlus	<a href="http://www.porfiria.it">www.porfiria.it</a>	Associate Member
Italy	Angeli Noonan	<a href="http://www.angelinoonan.it">www.angelinoonan.it</a>	Full Member
Italy	Associazione Persone con Malattie Reumatiche – APMAR Onlus	<a href="http://www.apmar.it">www.apmar.it</a>	Full Member
Italy	Associazione Conto Alla Rovescia	<a href="http://www.acar2006.org">www.acar2006.org</a>	Full Member
Italy	Associazione Del Bambino Emopatico	<a href="http://www.associazionebambinoemopatico.it">www.associazionebambinoemopatico.it</a>	Full Member
Italy	Associazione Famiglie di Soggetti con Deficit Dell'ormone della Crescita ed altre Patologie	<a href="http://www.afadoc.it">www.afadoc.it</a>	Full Member
Italy	Associazione Italiana Cistite Interstiziale	<a href="http://www.aici-onlus.it">www.aici-onlus.it</a>	Full Member
Italy	Associazione Italiana dei Cardiopatici Congeniti Adulti - Italian GUCH Association	<a href="http://www.aicca.eu">www.aicca.eu</a>	Associate Member
Italy	Associazione Italiana Estrofia Vescicale-Epispadia Onlus	<a href="http://www.estrofiavescicale.it">www.estrofiavescicale.it</a>	Full Member
Italy	Associazione Italiana Gaucher Onlus - AIG	<a href="http://www.gaucheritalia.org">www.gaucheritalia.org</a>	Full Member
Italy	Associazione Italiana Glicogenosi	<a href="http://www.aig-aig.it">www.aig-aig.it</a>	Full Member
Italy	Associazione Italiana Leucodistrofie Unite (AILU)	<a href="http://digilander.libero.it/ailu/">http://digilander.libero.it/ailu/</a>	Full Member
Italy	Associazione Italiana Linfoistocitosi Emofagocitica	<a href="http://www.aileonlus.org">www.aileonlus.org</a>	Associate Member
Italy	Associazione Italiana Malati di Alcaptonuria	<a href="http://www.aimaku.it">www.aimaku.it</a>	Full Member
Italy	Associazione Italiana malformazione di Arnold-Chiari Child	<a href="http://www.arnold-chiari.it">www.arnold-chiari.it</a>	Full Member
Italy	Associazione Italiana Miastenia e Malattie Immunodegenerative - Amici del Besta onlus	<a href="http://www.miastenia.it">www.miastenia.it</a>	Full Member
Italy	Associazione Italiana Miastenia Onlus	<a href="http://www.viverelamiastenia.it">www.viverelamiastenia.it</a>	Full Member
Italy	Associazione Italiana Mucopolisaccaridosi e Malattie Affini	<a href="http://www.aimps.it">www.aimps.it</a>	Full Member
Italy	Associazione Italiana Niemann Pick e Malattie Affini - Onlus	<a href="http://www.niemannpick.org">www.niemannpick.org</a>	Full Member
Italy	Associazione Italiana per la lotta alle PHTS	<a href="http://www.ptenitalia.org">www.ptenitalia.org</a>	Full Member
Italy	Associazione Italiana per le Malformazioni Anorettali	<a href="http://www.aimar.eu">www.aimar.eu</a>	Full Member
Italy	Associazione Italiana Sclerosi Laterale Amiotrofica (Sez. Lombardia)	<a href="http://www.aisla.it">http://www.aisla.it</a>	Full Member
Italy	Associazione Italiana Sindrome di Poland	<a href="http://www.sindromedipoland.org">www.sindromedipoland.org</a>	Full Member
Italy	Associazione Italiana Sindrome e Malattia di Behçet (SIMBA)	<a href="http://www.behcet.it">www.behcet.it</a>	Full Member
Italy	Associazione Italiana Siringomielia e Arnold Chiari	<a href="http://www.aismac.org">www.aismac.org</a>	Full Member
Italy	Associazione Italiana Sostegno Malattie Metaboliche Ereditarie Onlus	<a href="http://www.aismme.org">www.aismme.org</a>	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 Italiana Malati Sindrome di Sjogren		Full Member
Italy	Associazione per l'informazione e lo Studio della Acondroplasia	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	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	Incontinentia Pigmenti Associazione Italiana Onlus	www.incontinentiapigmenti.it	Associate Member
Italy	Lega Italiana Sclerosi Sistemica Onlus	www.sclerosistemica.info	Full Member
Italy	LND Famiglie Italiane Onlus	www.lnd-it.com	Full Member
Italy	p63 EEC Syndrome International network 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 - Federazione Italiana Malattie Rare	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 "Caladrius"		Associate Member
Lebanon	Lebanese association for neuromuscular diseases	landforhope.org	Associate Member
Lithuania	Community of Oncohematological Patient Organisations KRAUJAS	www.kraujas.lt	Full Member
Luxembourg	ALAN - Rare Diseases 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	European Society for Phenylketonuria	www.espku.org	Associate Member
Netherlands	European VHL (von Hippel-Lindau) Federation	www.vhl-europa.org	Associate Member
Netherlands	European Waldenström Macroglobulinemia Network	www.waldenstrom.eu	Full Member
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	www.fshd-Europe.org	Full Member
Netherlands	International Mito Patients	www.mitopatients.org	Full Member

Netherlands	International Painful Bladder Foundation	<a href="http://www.painful-bladder.org">www.painful-bladder.org</a>	Associate Member
Netherlands	International Porphyria Patient Network	<a href="http://www.ippn.info">www.ippn.info</a>	Associate Member
Netherlands	Interstitiële cystitis Patientenvereniging	<a href="http://www.icpatienten.nl">www.icpatienten.nl</a>	Full Member
Netherlands	ITP Patientenvereniging	<a href="http://www.itp-pv.nl">www.itp-pv.nl</a>	Full Member
Netherlands	KAISZ children with a autoimmuun or autoinflammatory disease	<a href="http://www.kaisz.nl">www.kaisz.nl</a>	Full Member
Netherlands	MSS (Marshall-Smith Syndrome) Research Foundation	<a href="http://www.marshallsmith.org">www.marshallsmith.org</a>	Full Member
Netherlands	Nederlands Netwerk voor Lymfoedeem en Lipoedeem	<a href="http://www.lymfoedeem.nl">www.lymfoedeem.nl</a>	Associate Member
Netherlands	Nederlandse Hypofyse Stichting (Dutch Pituitary Foundation)	<a href="http://www.hypofyse.nl">www.hypofyse.nl</a>	Full Member
Netherlands	Nederlandse Phenylketonurie Vereniging / Dutch PKU Association	<a href="http://www.pkuvereniging.nl">Www.pkuvereniging.nl</a>	Full Member
Netherlands	NephcEurope	<a href="http://nephceurope.eu/nc/">http://nephceurope.eu/nc/</a>	Associate Member
Netherlands	Netherlands Association of Patients with Sterno Costo Clavicular Hyperostosis	<a href="http://www.scch.nl">www.scch.nl</a>	Full Member
Netherlands	Netherlands Liver Patients Association	<a href="http://www.leverpatientenvereniging.nl">www.leverpatientenvereniging.nl</a>	Full Member
Netherlands	Neurofibromatose Vereniging Nederland	<a href="http://www.neurofibromatose.nl">www.neurofibromatose.nl</a>	Full Member
Netherlands	OSCAR Nederland	<a href="http://www.oscarnederland.nl">www.oscarnederland.nl</a>	Full Member
Netherlands	PSC Patients Europe	<a href="http://pscpatientseurope.org">http://pscpatientseurope.org</a>	Full Member
Netherlands	Sarcoidose Belangenvereniging Nederland	<a href="http://www.sarcoidose.nl">www.sarcoidose.nl</a>	Full Member
Netherlands	Stichting AA & PNH contactgroep	<a href="http://www.aaenphn.nl">http://www.aaenphn.nl</a>	Full Member
Netherlands	Stichting Amyloidose Nederland SAN	<a href="http://amyloidose.nl">amyloidose.nl</a>	Full Member
Netherlands	Stichting Histiocytose Nederland	<a href="http://www.histio.nl">www.histio.nl</a>	Full Member
Netherlands	Stichting Ijzersterk	<a href="http://www.stichtingijzersterk.nl">www.stichtingijzersterk.nl</a>	Associate Member
Netherlands	Stichting NET-groep	<a href="http://www.net-kanker.nl">www.net-kanker.nl</a>	Full Member
Netherlands	Stichting Shwachman Diamond Syndrome Support Holland	<a href="http://www.shwachman.nl">www.shwachman.nl</a>	Full Member
Netherlands	Stichting Stofwisselkracht	<a href="http://www.stofwisselkracht.nl">www.stofwisselkracht.nl</a>	Full Member
Netherlands	Stichting Terre - Rett Syndrome Foundation	<a href="http://www.stichtingterre.nl">www.stichtingterre.nl</a>	Full Member
Netherlands	STICHTING VOOR AFWEERSTOORNISSEN	<a href="http://www.stichtingvoorafweerstoornissen.nl">www.stichtingvoorafweerstoornissen.nl</a>	Full Member
Netherlands	United Parent Projects Muscular Dystrophy	<a href="http://www.uppmd.org">www.uppmd.org</a>	Full Member
Netherlands	Vasculitis Stichting (formerly known as Friedrich Wegener Stichting)	<a href="http://www.vasculitis.nl">www.vasculitis.nl</a>	Full Member
Netherlands	Vereniging Samenwerkende Ouder En Patiëntenorganisaties (VSOP)	<a href="http://www.vsop.nl">www.vsop.nl</a>	Full Member
Netherlands	Vereniging Spierziekten Nederland - Dutch Association For Neuromuscular Disease	<a href="http://www.vsn.nl">www.vsn.nl</a>	Full Member
Netherlands	Volwassenen, Kinderen en Stofwisselingsziekten	<a href="http://www.stofwisselingsziekten.nl">www.stofwisselingsziekten.nl</a>	Full Member
Netherlands	World Alliance of Pituitary Organizations	<a href="http://www.wapo.org">www.wapo.org</a>	Associate Member
New Zealand	New Zealand Organisation for Rare Disorders	<a href="http://www.nzord.org.nz/">www.nzord.org.nz/</a>	Associate Member
Norway	Aniridi Norge	<a href="http://www.aniridi.no">www.aniridi.no</a>	Full Member

Norway	Aniridia Europe	<a href="http://www.aniridia.eu">www.aniridia.eu</a>	Full Member
Norway	FRAMBU - Resource Centre for Rare Disorders	<a href="http://www.frambu.no">www.frambu.no</a>	Full Member
Norway	Morbus Addison Association Norway	<a href="http://www.addison.no">www.addison.no</a>	Full Member
Norway	MPS foreningen Norge		Associate Member
Norway	Nordic hypoPARA Organisation	<a href="http://www.hypopara-nordic.org">www.hypopara-nordic.org</a>	Full Member
Norway	Norsk forening for Arvelig Spastisk Paraparese / Ataksi	<a href="http://www.naspa.no">www.naspa.no</a>	Full Member
Norway	NORSK FORENING FOR EHLERS-DANLOS SYNDROM	<a href="http://www.eds-foreningen.no">www.eds-foreningen.no</a>	Full Member
Norway	Norsk Forening for Osteogenesis Imperfecta	<a href="http://www.nfoi.no">www.nfoi.no</a>	Full Member
Norway	Norsk Forening for Tuberos Sklerose	<a href="http://www.nfts.no">www.nfts.no</a>	Full Member
Norway	Oslerforeningen Norge	<a href="http://www.osler.no">www.osler.no</a>	Full Member
Poland	Debra Polska	<a href="http://www.debra-kd.pl">www.debra-kd.pl</a>	Full Member
Poland	Fundacja Sanfilippo	<a href="http://www.sanfilippo.org.pl">www: sanfilippo.org.pl</a>	Associate Member
Poland	Fundacja SMA (SMA Foundation Poland)	<a href="http://www.fsma.pl">www.fsma.pl</a>	Full Member
Poland	Fundacja Umiec Pomagac (Foundation for RD MPS )	<a href="http://www.umiecpomagac.org">www.umiecpomagac.org</a>	Full Member
Poland	MATIO-Fundacji Pomocy Rodzinom i Chorym na Mukowiscydozę	<a href="http://www.mukowiscydoza.pl">www.mukowiscydoza.pl</a>	Full Member
Poland	Polish National Forum on the Treatment of Orphan Diseases - ORPHAN	<a href="http://www.rzadkiechoroby.pl">www.rzadkiechoroby.pl</a>	Full Member
Poland	Polish PKU and RD Association "Ars Vivendi"	<a href="http://www.fenyloketonuria.org">www.fenyloketonuria.org</a>	Full Member
Poland	Polish Society of MPS and Related Diseases	<a href="http://www.mps-society.pl">www.mps-society.pl</a>	Full Member
Poland	Polskie Stowarzyszenie na Rzecz Osób z AHC		Associate Member
Poland	The Dina Radziwillowa Child's Heart Foundation	<a href="http://www.sercedziecka.org.pl">www.sercedziecka.org.pl</a>	Full Member
Portugal	Aliança Portuguesa de Associações das Doenças Raras	<a href="http://aliancadoencasraras.org/">http://aliancadoencasraras.org/</a>	Associate Member
Portugal	APLL - Associação Portuguesa de Leucemias e Linfomas	<a href="http://www.apll.org">www.apll.org</a>	Full Member
Portugal	Associação Nacional de Displasias Ósseas	<a href="http://www.andoportugal.org">www.andoportugal.org</a>	Associate Member
Portugal	ASSOCIAÇÃO NACIONAL DE FIBROSE QUISTICA	<a href="http://www.anfq.pt">www.anfq.pt</a>	Full Member
Portugal	Associação Portuguesa CDG e outras Doenças Metabólicas	<a href="http://www.apcdg.com">www.apcdg.com</a>	Associate Member
Portugal	Associação Portuguesa de Charcot-Marie-Tooth	<a href="http://apcmt.org.pt">apcmt.org.pt</a>	Full Member
Portugal	ASSOCIAÇÃO PORTUGUESA DE DOENTES NEUROMUSCULARES	<a href="http://www.apn.pt">www.apn.pt</a>	Full Member
Portugal	Associação Sanfilippo Portugal	<a href="http://www.sanfilippoportugal.com">www.sanfilippoportugal.com</a>	Associate Member
Portugal	FEDRA - Federação Portuguesa de Doenças Raras	<a href="http://www.fedra.pt">www.fedra.pt</a>	Associate Member
Portugal	Rarissimas - Associação Nacional de Deficiências Mentais e Raras	<a href="http://www.rarissimas.pt">www.rarissimas.pt</a>	Full Member
Romania	Asociatia Copilul Meu-Inima Mea	<a href="http://www.acmim.ro">www.acmim.ro</a>	Full Member
Romania	Asociatia Persoanelor Cu Talasemie Majora	<a href="http://www.talasemia.ro">www.talasemia.ro</a>	Full Member
Romania	Asociația Română de Cancere Rar	<a href="http://www.arcrareromania.ro">www.arcrareromania.ro</a>	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	www.cfhelp.ru	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.rettssyndrome.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 Genetickych Ochorenie	http://www.zogo.sk/	Associate Member
Slovenia	Association of patients with blood diseases - Drustvo Bolnikv 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	<a href="http://pednevro.pedkl.si/english/foundation/">http://pednevro.pedkl.si/english/foundation/</a>	Associate Member
South Africa	Primary Immunodeficiency Network of South Africa	<a href="http://www.pinsa.org.za">www.pinsa.org.za</a>	Associate Member
South Africa	Rare Disease Society of South Africa	<a href="http://www.rarediseases.co.za">www.rarediseases.co.za</a>	Associate Member
Spain	Acción y Cura para Tay-Sachs - ACTAYS	<a href="http://www.actays.org">www.actays.org</a>	Full Member
Spain	Alianza Española de Familias de Von Hippel Lindau	<a href="http://www.alianzavhl.org">www.alianzavhl.org</a>	Full Member
Spain	ASOCIACIÓ CATALANA DE LAS NEUROFIBROMATOSIS	<a href="http://www.acnefi.com/castella/gamhome.htm">http://www.acnefi.com/castella/gamhome.htm</a>	Full Member
Spain	ASOCIACIÓ D'AFECTATS DE SIRINGOMIÈLIA	<a href="http://www.siringomielia.org">www.siringomielia.org</a>	Full Member
Spain	ASOCIACIÓN ANDALUZA CONTRA LA FIBROSIS QUÍSTICA	<a href="http://www.fibrosisquistica.org/andaluza/">www.fibrosisquistica.org/andaluza/</a>	Full Member
Spain	Asociación Andaluza de Pacientes con Síndrome de Tourette y Trastornos Asociados	<a href="http://www.tourette.es">www.tourette.es</a>	Full Member
Spain	Asociacion Chiari y Siringomielia del Principado de Asturias	<a href="http://www.chyspa.org">www.chyspa.org</a>	Full Member
Spain	ASOCIACIÓN DE AFECTADOS DE NEUROFIBROMATOSIS	<a href="http://www.neurofibromatosis.es">www.neurofibromatosis.es</a>	Full Member
Spain	ASOCIACIÓN DE AFECTADOS POR DISPLASIA ECTODÉRMICA	<a href="http://www.displasiaectodermica.org">www.displasiaectodermica.org</a>	Full Member
Spain	Asociación de Afectados por Hiperinsulinismo Congénito	<a href="http://www.afhico.org">www.afhico.org</a>	Full Member
Spain	Asociacion de Atrofia de Nervio Optico de Leber	<a href="http://www.asanol.com">www.asanol.com</a>	Full Member
Spain	Asociación de Epidermolisis Bullosa de España (DEBRA España)	<a href="http://www.debra.es">www.debra.es</a>	Full Member
Spain	Asociación de Esclerodermia Castellon	<a href="http://www.esclerodermia-adec.org">www.esclerodermia-adec.org</a>	Full Member
Spain	Asociacion de Familiares y afectados por Lipodistrofias	<a href="http://www.aelip.org">www.aelip.org</a>	Full Member
Spain	Asociacion de Familiares y Enfermos de FPI y FPF	<a href="http://www.afefpi.org">www.afefpi.org</a>	Full Member
Spain	Asociación de Hemoglobinuria Paroxística Nocturna	<a href="http://www.hpne.org">www.hpne.org</a>	Associate Member
Spain	ASOCIACIÓN DE HUESOS DE CRISTAL DE ESPAÑA	<a href="http://www.ahuce.org">www.ahuce.org</a>	Full Member
Spain	ASOCIACIÓN DE LAS MUCOPOLISACARIDOSIS Y SÍNDROMES RELACIONADOS	<a href="http://www.mpsesp.org/">www.mpsesp.org/</a>	Full Member
Spain	ASOCIACIÓN DE NEVUS GIGANTE CONGÉNITO	<a href="http://asonevus.org/">http://asonevus.org/</a>	Full Member
Spain	Asociacion española del síndrome CDG, defectos congénitos de la glicosilacion	<a href="http://webs.ono.com/aescdg">http://webs.ono.com/aescdg</a>	Associate Member
Spain	Asociación Española Aniridia	<a href="http://www.aniridia.es">www.aniridia.es</a>	Full Member
Spain	Asociación Española De Angioedema Familiar	<a href="http://www.angioedema-aedaf.org">www.angioedema-aedaf.org</a>	Full Member
Spain	Asociación Española de Enfermos de Glucogenosis	<a href="http://www.glucogenosis.org">www.glucogenosis.org</a>	Full Member

Spain	Asociación Española de Enfermos y Familiares de la Enfermedad de Gaucher España	<a href="http://www.aeefegaucher.es">www.aeefegaucher.es</a>	Full Member
Spain	Asociación Española de Esclerodermia	<a href="http://www.esclerodermia.com">www.esclerodermia.com</a>	Full Member
Spain	Asociación Española de Familiares y Enfermos de Wilson	<a href="http://www.enfermedaddewilson.org">www.enfermedaddewilson.org</a>	Full Member
Spain	Asociación Española de Fibrodisplasia Osificante Progresiva	<a href="http://www.aefop-es.org">www.aefop-es.org</a>	Full Member
Spain	Asociación Española de Fiebre Mediterranea Familiar	<a href="http://fmf.org.es">http://fmf.org.es</a>	Full Member
Spain	Asociación Española de Ictiosis	<a href="http://www.ictiosis.org">www.ictiosis.org</a>	Full Member
Spain	Asociación Española de Paraparesia Espástica Familiar Strümpell-Lorrain	<a href="http://www.aepef.org">www.aepef.org</a>	Full Member
Spain	Asociación Española de Porfiria	<a href="http://www.porfiria.org">www.porfiria.org</a>	Full Member
Spain	Asociación Española de Síndrome De Poland	<a href="http://www.aesip.es">www.aesip.es</a>	Full Member
Spain	Asociación Española del Síndrome de Joubert	<a href="http://webs.ono.com/sindrome_joubert/">http://webs.ono.com/sindrome_joubert/</a>	Full Member
Spain	Asociación Española Síndrome de Sjögren	<a href="http://www.aesjogren.org">www.aesjogren.org</a>	Full Member
Spain	Asociación HHT España	<a href="http://www.asociacionhht.org">www.asociacionhht.org</a>	Full Member
Spain	Asociación Lupus de Málaga y Autoinmunes	<a href="http://lupusmalagayautoinmunes.org/lupus-">http://lupusmalagayautoinmunes.org/lupu</a>	Full Member
Spain	Asociación Miradas que Hablan Duplicación Mecp2	<a href="http://www.duplicacionmecp2.es">www.duplicacionmecp2.es</a>	Full Member
Spain	Asociación Nacional Amigos de Arnold Chiari	<a href="http://www.chiari.biz">www.chiari.biz</a>	Full Member
Spain	Asociación Nacional de Hipertensión Pulmonar	<a href="http://www.hipertensionpulmonar.es">www.hipertensionpulmonar.es</a>	Full Member
Spain	Asociación Nacional Síndrome de Apert y otras Craneosinostosis Sindrómicas	<a href="http://www.ansapert.org">www.ansapert.org</a>	Full Member
Spain	Asociación Síndrome de Angelman	<a href="http://www.angelman-asa.org">www.angelman-asa.org</a>	Full Member
Spain	Asociación Síndrome de Lowe de España	<a href="http://www.sindromelowe.es">www.sindromelowe.es</a>	Full Member
Spain	Asociación Síndrome Lesch Nyhan España	<a href="http://www.asociacionlesch-nyhan.org.es">www.asociacionlesch-nyhan.org.es</a>	Full Member
Spain	Asociación Stop Sanfilippo	<a href="http://www.stopsanfilippo.org">www.stopsanfilippo.org</a>	Associate Member
Spain	Associació Catalana de la Delecció 22Q	<a href="http://www.22q.cat">www.22q.cat</a>	Full Member
Spain	Associació Catalana de Síndrome de Sjögren		Full Member
Spain	Associació d'Apràxia Ocular i Malalties Associades	<a href="http://apraxiaocular.blogspot.com">apraxiaocular.blogspot.com</a>	Associate Member
Spain	Associació Catalana de Enfermedades Neuromusculares	<a href="http://www.asemcatalunya.com">www.asemcatalunya.com</a>	Full Member
Spain	D'Genes Asociación de Enfermedades Raras de Murcia	<a href="http://www.dgenes.es/">http://www.dgenes.es/</a>	Full Member
Spain	Dravet Syndrome Foundation, Delegación en España	<a href="http://www.dravetfoundation.eu">www.dravetfoundation.eu</a>	Associate Member
Spain	Duchenne Parent Project España	<a href="http://www.duchenne-spain.org">www.duchenne-spain.org</a>	Full Member
Spain	European Network for Rare and Congenital Anaemias	<a href="http://www.enerca.org">www.enerca.org</a>	Associate Member
Spain	Federació Catalana de Malalties Minoritàries	<a href="http://www.fcmpf.entitatsbcn.net">www.fcmpf.entitatsbcn.net</a>	Full Member
Spain	Federación de Asociaciones de Retinosis Pigmentaria de España	<a href="http://www.retinosisfarpe.org">www.retinosisfarpe.org</a>	Full Member
Spain	Federación de Ataxias de España	<a href="http://www.fedaes.org">www.fedaes.org</a>	Full Member
Spain	Federación Española de Enfermedades Neuromusculares	<a href="http://www.asem-esp.org">www.asem-esp.org</a>	Full Member

Spain	Federación Española de Enfermedades Raras	www.enfermedades-raras.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 Síndrome de West	www.sindromedewest.org	Full Member
Spain	Fundación Síndrome Wolf Hirschhorn o 4p-	www.4pmenos.org	Full Member
Spain	hipertension pulmonar españa organizacion de pacientes - Hpe-org	www.hipertension-pulmonar.com	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	Neurologiskt Handikappades Riksförbund / Swedish Association of persons with Neurological disabilities	www.nhr.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.asrim.ch	Full Member
Switzerland	Blackswan Foundation	www.blackswanfoundation.ch	Associate Member
Switzerland	FMF & AID Global Association	www.fmfandaaid.org	Associate Member

Switzerland	Fondation Sanfilippo Suisse	<a href="http://www.fondation-sanfilippo.org">www.fondation-sanfilippo.org</a>	Associate Member
Switzerland	Foundation Orphanhealthcare	<a href="http://www.orphanhealthcare.com">www.orphanhealthcare.com</a>	Associate Member
Switzerland	FRAXAS - Association X Fragile Suisse	<a href="http://www.fraxas.ch">www.fraxas.ch</a>	Full Member
Switzerland	HAEi - Hereditary Angioedema International Association	<a href="http://www.haei.org">http://www.haei.org</a>	Associate Member
Switzerland	HHT-Swiss		Associate Member
Switzerland	Leukemia Patient Advocates Foundation	<a href="http://www.cmladvocates.net">www.cmladvocates.net</a>	Associate Member
Switzerland	Marfan Foundation Switzerland (Marfan Stiftung Schweiz)	<a href="http://www.marfan.ch">www.marfan.ch</a>	Full Member
Switzerland	Prader Willi Syndrom Vereinigung Schweiz	<a href="http://www.prader-willi.ch">www.prader-willi.ch</a>	Full Member
Switzerland	ProRaris	<a href="http://www.proraris.ch">www.proraris.ch</a>	Full Member
Switzerland	Retina International	<a href="http://www.retina-international.org">www.retina-international.org</a>	Full Member
Switzerland	Schweizerische Gesellschaft für Porphyrie	<a href="http://www.porphyrria.ch">www.porphyrria.ch</a>	Full Member
Switzerland	Selbsthilfe Ichthyose Schweiz	<a href="http://www.ichthyose.ch">www.ichthyose.ch</a>	Associate Member
Switzerland	SMA Schweiz	<a href="http://www.sma-schweiz.ch">www.sma-schweiz.ch</a>	Associate Member
Taiwan, Province Of China	Taiwan Foundation for Rare Disorders	<a href="http://www.tfrd.org.tw">www.tfrd.org.tw</a>	Associate Member
The Former Yugoslav Republic	Life with Challenges	<a href="http://challenges.mk/">http://challenges.mk/</a>	Full Member
The Former Yugoslav Republic	National Alliance for Rare Diseases of R. Macedonia		Full Member
The Former Yugoslav Republic	Save Liver Association of Patients with liver diseases	<a href="https://facebook.com/SLAPSaveLiverAssociationforPatients">facebook/SLAPSaveLiverAssociationforPatients</a>	Full Member
The Former Yugoslav Republic	Zdruzenie za Cisticna Fibroza (Macedonian CF Association)	<a href="http://www.cf.mk">www.cf.mk</a>	Full Member
Turkey	KifDER	<a href="http://www.kistikfibrozis.org.tr">www.kistikfibrozis.org.tr</a>	Associate Member
Turkey	Mukopolisakkaridoz ve Benzeri Lizozomal Depo Hastaliklari Dernegi	<a href="http://www.mpsturk.org">www.mpsturk.org</a>	Associate Member
Ukraine	Association of patients with pulmonaty hypertension	<a href="http://www.pha.org.ua">www.pha.org.ua</a>	Full Member
Ukraine	Charitable Foundation of Sister Dalila	<a href="http://poryatunok.info/uk/">http://poryatunok.info/uk/</a>	Associate Member
Ukraine	Kharkiv's Charitable Foundation - "Children with Spinal Muscular Atrophy"	<a href="http://www.csma.org.ua">www.csma.org.ua</a>	Full Member
Ukraine	Non-governmental Organization "Rare Diseases of Ukraine"	<a href="http://rarediseases.org.ua/index.php/en/">http://rarediseases.org.ua/index.php/en/</a>	Associate Member
Ukraine	Ukrainian Association Crystal People	<a href="http://ostimperfecta.wix.com/oiua">http://ostimperfecta.wix.com/oiua</a>	Associate Member
Ukraine	Ukrainian National charitable fund ZAPORUKA	<a href="http://www.zaporuka.com.ua">www.zaporuka.com.ua</a>	Associate Member
Ukraine	Ukrainian Union of Patients' Organisations	<a href="http://www.patient.in.ua">www.patient.in.ua</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	Advocacy for Neuroacanthocytosis Patients	<a href="http://www.naadvocacy.org">www.naadvocacy.org</a>	Associate Member

United Kingdom Of Great Britain And Northern Ireland	AKU Society	<a href="http://www.akusociety.org">http://www.akusociety.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	ALD LIFE	<a href="http://www.aldlife.org">www.aldlife.org</a>	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	<a href="http://www.alstrom.org.uk">www.alstrom.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Ann Edgar Charitable Trust - Neuroendocrine Tumour Support	<a href="http://www.taect.scot">www.taect.scot</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Annabelle's Challenge	<a href="http://www.annabelleschallenge.org">www.annabelleschallenge.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Association for Glycogen Storage Disease	<a href="http://www.agsd.org.uk">www.agsd.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Association for Multiple Endocrine Neoplasia Disorders	<a href="http://www.amend.org.uk">www.amend.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Ataxia UK	<a href="http://www.ataxia.org.uk">www.ataxia.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Batten Disease Family Association	<a href="http://www.bdfa-uk.org.uk/about-batten-disease">http://www.bdfa-uk.org.uk/about-batten-disease</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Behcets Syndrome Society	<a href="http://www.behcets.org.uk">www.behcets.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Brittle Bone Society	<a href="http://www.brittlebone.org">www.brittlebone.org</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	Cancer 52	<a href="http://www.cancer52.org.uk">www.cancer52.org.uk</a>	Associate Member

United Kingdom Of Great Britain And Northern Ireland	Cavernoma Alliance UK	<a href="http://www.cavernoma.org.uk">www.cavernoma.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Child Growth Foundation	<a href="http://www.childgrowthfoundation.org">www.childgrowthfoundation.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	ChILD Lung Foundation	<a href="http://www.childlungfoundation.org">www.childlungfoundation.org</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	Children Living With Inherited Metabolic Diseases	<a href="http://www.climb.org.uk">www.climb.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Ciliopathy Alliance	<a href="http://www.ciliopathyalliance.org">www.ciliopathyalliance.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	CONTACT A FAMILY	<a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Cystinosis Foundation of the UK	<a href="http://www.cystinosis.org.uk">www.cystinosis.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Dancing Eye Syndrome Support Trust	<a href="http://www.dancingeyes.org.uk">www.dancingeyes.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Degos Disease Support Network	<a href="http://www.degosdisease.com">www.degosdisease.com</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	Ectodermal Dysplasia Society	<a href="http://www.ectodermaldysplasia.org">www.ectodermaldysplasia.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	European Gaucher Alliance	<a href="http://www.eurogaucher.org">www.eurogaucher.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	European Myasthenia Gravis Association	<a href="http://www.eumga.eu">www.eumga.eu</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	European Tuberous Sclerosis Complex Association	<a href="http://www.e-tsc.eu">www.e-tsc.eu</a>	Full Member

United Kingdom Of Great Britain And Northern Ireland	Fabry International Network	<a href="http://www.fabrynetwork.org/">www.fabrynetwork.org/</a>	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	<a href="http://www.findacure.org.uk">www.findacure.org.uk</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	FOP Friends	<a href="http://www.fopfriends.com">www.fopfriends.com</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Gauchers Association UK	<a href="http://www.gaucher.org.uk">www.gaucher.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Genetic Alliance UK	<a href="http://www.geneticalliance.org.uk">www.geneticalliance.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	International Brain Tumour Alliance	<a href="http://www.theibta.org">www.theibta.org</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	International Niemann-Pick Disease Alliance	<a href="http://www.inpda.org">www.inpda.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	IPOPI - International Patient Organization for Primary Immunodeficiencies	<a href="http://www.ipopi.org">www.ipopi.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Joining Jack	<a href="http://www.joiningjack.org">www.joiningjack.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Leber's Hereditary Optic Neuropathy Society	<a href="http://www.lhonsociety.org">www.lhonsociety.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Lymphangiomatosis & Gorham Disease Alliance Europe	<a href="http://www.lgda.eu">www.lgda.eu</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Max Appeal	<a href="http://www.maxappeal.org.uk">www.maxappeal.org.uk</a>	Full Member



United Kingdom Of Great Britain And Northern Ireland	MEBO Research	<a href="http://www.meboresearch.org">www.meboresearch.org</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	MPS Society	<a href="http://www.mpssociety.co.uk">www.mpssociety.co.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	myaware	<a href="http://www.myaware.org/">www.myaware.org/</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Myotubular Trust	<a href="http://www.myotubulartrust.org">www.myotubulartrust.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Newlife Foundation for Disabled Children	<a href="http://www.bdfnewlife.co.uk">www.bdfnewlife.co.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	NIEMANN-PICK DISEASE GROUP UK	<a href="http://www.niemann-pick.org.uk">www.niemann-pick.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Northern Ireland Rare Disease Partnership	<a href="http://www.nirdp.org.uk">www.nirdp.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	One in a million - Pseudomyxoma Survivor	<a href="http://www.pseudomyxomasurvivor.co.uk">www.pseudomyxomasurvivor.co.uk</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	Organisation for Anti-Convulsant Syndrome	<a href="http://www.oacscharity.org">www.oacscharity.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Polycystic Kidney Disease Charity (PKDC)	<a href="http://www.pkdcharity.org.uk">www.pkdcharity.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Prader Willi Syndrome Association UK	<a href="http://www.pwsa.co.uk">www.pwsa.co.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	PSC Support	<a href="http://www.pscsupport.org.uk">www.pscsupport.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Rare Autoinflammatory Conditions' Community UK	<a href="http://www.raccuk.com">www.raccuk.com</a>	Associate Member

United Kingdom Of Great Britain And Northern Ireland	Rare Diseases UK	<a href="http://www.raredisease.org.uk">www.raredisease.org.uk</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	Ring 20 Research and Support UK CIO	<a href="http://ring20researchsupport.co.uk/">http://ring20researchsupport.co.uk/</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	Spinal Muscular Atrophy Support UK	<a href="http://www.smasupportuk.org.uk">www.smasupportuk.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Stiff Person Support Group	<a href="http://www.smssupportgroup.co.uk">www.smssupportgroup.co.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Sturge-Weber UK	<a href="http://www.sturgeweber.org.uk">www.sturgeweber.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Syncope Trust and Reflex Anoxic Seizures	<a href="http://www.stars.org.uk">www.stars.org.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	The AADC Research Trust Children's Charity	<a href="http://www.aadcresearch.org">www.aadcresearch.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	The Chromosome 18 Registry and Research Society (Europe)	<a href="http://www.chromosome18eur.org">www.chromosome18eur.org</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	The Cure & Action for Tay-Sachs (CATS) Foundation	<a href="http://www.cats-foundation.org">www.cats-foundation.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	The Fragile X Society	<a href="http://www.fragilex.org.uk/">www.fragilex.org.uk/</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	The PBC Foundation (UK) Ltd	<a href="http://www.pbcfoundation.org.uk">www.pbcfoundation.org.uk</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	The Ultra Rare Diseases, Disorders & Disabilities Foundation	<a href="http://www.ultrarare-disease.uk">www.ultrarare-disease.uk</a>	Associate Member
United Kingdom Of Great Britain And Northern Ireland	Tuberous Sclerosis Association	<a href="http://www.tuberous-sclerosis.org">www.tuberous-sclerosis.org</a>	Full Member

United Kingdom Of Great Britain And Northern Ireland	UK Mastocytosis Support Group	<a href="http://www.ukmasto.co.uk">www.ukmasto.co.uk</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Unique - The Rare Chromosome Disorder Support Group	<a href="http://www.rarechromo.org">www.rarechromo.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	United Kingdom Thalassaemia Society	<a href="http://www.ukts.org">www.ukts.org</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Uveitis Information Group	<a href="http://www.uveitis.net">www.uveitis.net</a>	Full Member
United Kingdom Of Great Britain And Northern Ireland	Vasculitis UK (The Vasculitis Trust)	<a href="http://www.vasculitis.org.uk">www.vasculitis.org.uk</a>	Full Member
United States	Alstrom Syndrome International	<a href="http://www.alstrom.org">www.alstrom.org</a>	Associate Member
United States	APS Foundation of America, Inc (APSFA)	<a href="http://www.apsfa.org">www.apsfa.org</a>	Associate Member
United States	Chordoma Foundation	<a href="http://www.chordoma.org">www.chordoma.org</a>	Associate Member
United States	Cure PSP	<a href="http://www.curepsp.org">www.curepsp.org</a>	Associate Member
United States	Cystinosis Foundation	<a href="http://www.cystinosisfoundation.org">www.cystinosisfoundation.org</a>	Associate Member
United States	FMD Chat	<a href="http://fmdchat.blogspot.fr/">http://fmdchat.blogspot.fr/</a>	Associate Member
United States	International Pemphigus & Pemphigoid Foundation	<a href="http://www.pemphigus.org">www.pemphigus.org</a>	Associate Member
United States	International Waldenstrom's Macroglobulinemia Foundation	<a href="http://www.iwmf.com">www.iwmf.com</a>	Associate Member
United States	NORD National Organization For Rare Disorders	<a href="http://www.rarediseases.org">www.rarediseases.org</a>	Associate Member
United States	NTM Info & Research	<a href="http://www.ntminfo.org">www.ntminfo.org</a>	Associate Member
United States	PURA Syndrome Foundation	<a href="http://www.purasyndrome.org">www.purasyndrome.org</a>	Associate Member
United States	The Cushing Support & Research Foundation	<a href="http://www.csrf.net">www.csrf.net</a>	Associate Member
United States	The Oxalosis & Hyperoxaluria Foundation	<a href="http://www.ohf.org">www.ohf.org</a>	Associate Member
Uruguay	Asociacion Acondroplasia Uruguay	<a href="http://www.acondroplasiauruguay.org">www.acondroplasiauruguay.org</a>	Associate Member