

## EURODIS Members - May 2025

Country/Region	Organisation	Website	Membership
Albania	Shoqata e Semundjeve te Rralla / Rare Disease Association Albania	<a href="http://rda-al.com/">http://rda-al.com/</a>	Associate Member
Algeria	Association Elamani pour venir en aide aux Malades souffrant de l'Anémie Héréditaire		Associate Member
Andorra	Associació de Malalties Minoritàries d'Andorra	<a href="https://amma.ad/">https://amma.ad/</a>	Full Member
Argentina	Alianza Argentina de Pacientes	<a href="http://alianzapacientes.org/">http://alianzapacientes.org/</a>	Associate Member
Argentina	Federación Argentina de Enfermedades Poco Frecuentes	<a href="http://fadepof.org.ar/">http://fadepof.org.ar/</a>	Associate Member
Armenia	Doctors And Children Health Care	<a href="http://www.rambler.ru">http://www.rambler.ru</a>	Associate Member
Armenia	National Center for Rare Disease of Armenia	<a href="http://www.cmg.am">http://www.cmg.am</a>	Associate Member
Australia	Cystic Fibrosis Australia	<a href="http://www.cysticfibrosis.org.au">http://www.cysticfibrosis.org.au</a>	Associate Member
Australia	Genetic Alliance Australia	<a href="http://www.geneticalliance.org.au">http://www.geneticalliance.org.au</a>	Associate Member
Australia	Genetic Support Network of Victoria	<a href="https://www.gsnv.org.au/">https://www.gsnv.org.au/</a>	Associate Member
Australia	Muscular Dystrophy WA	<a href="https://www.mdwa.org.au/">https://www.mdwa.org.au/</a>	Associate Member
Australia	PURA Foundation Australia	<a href="https://www.purafoundation.au/">https://www.purafoundation.au/</a>	Associate Member
Australia	Rare Voices Australia	<a href="http://www.rarevoices.org.au">http://www.rarevoices.org.au</a>	Associate Member
Australia	Save our Sons	<a href="https://www.saveoursons.org.au/">https://www.saveoursons.org.au/</a>	Associate Member
Austria	Angelman Verein Österreich	<a href="http://www.angelman.at">http://www.angelman.at</a>	Full Member
Austria	CACNA1E International	<a href="https://www.cacna1e.org/">https://www.cacna1e.org/</a>	Full Member
Austria	Debra International	<a href="https://www.debra-international.org">https://www.debra-international.org</a>	Full Member
Austria	Hand in Hand Für Tay-Sachs & Palliativkinder	<a href="http://www.tay-sachs.net">http://www.tay-sachs.net</a>	Associate Member
Austria	ICA-Österreich	<a href="http://www.ica-austria.at">http://www.ica-austria.at</a>	Full Member
Austria	Lasst uns MDS heilen - DupMECP2	<a href="https://dupmecp2.eu/">https://dupmecp2.eu/</a>	Full Member
Austria	NF Kinder- Hilfe für Neurofibromatose- PatientInnen und Angehörige,	<a href="http://www.nfkinder.at">http://www.nfkinder.at</a>	Full Member
Austria	PH Austria - Initiative Lungenhochdruck	<a href="http://www.phaustria.org">http://www.phaustria.org</a>	Full Member
Austria	PHA Europe	<a href="http://www.phaeurope.org">http://www.phaeurope.org</a>	Associate Member
Austria	Pro Rare Austria, Allianz für seltenen Erkrankungen	<a href="http://www.prorare-austria.org">http://www.prorare-austria.org</a>	Full Member
Austria	Smith-Magenis-Syndrom Österreich	<a href="https://www.smith-magenis.at/">https://www.smith-magenis.at/</a>	Full Member
Austria	Usher Deafblind Forum Austria	<a href="http://www.usher-taubblind.at">http://www.usher-taubblind.at</a>	Associate Member
Belarus	Belarussian Organization of Patients with MPS and other Rare Genetic	<a href="http://www.mppsociety.by">http://www.mppsociety.by</a>	Full Member
Belgium	22Q11 Europe	<a href="https://22q11europe.org/">https://22q11europe.org/</a>	Associate Member
Belgium	Alpha-1 Europe Alliance asbl	<a href="https://alpha1europe.org/">https://alpha1europe.org/</a>	Associate Member
Belgium	Alpha-1 Plus asbnl	<a href="https://alpha1plus.be/">https://alpha1plus.be/</a>	Associate Member
Belgium	ALS Liga België	<a href="http://www.alsliga.be">http://www.alsliga.be</a>	Full Member
Belgium	Amyloïdose Vereniging België	<a href="https://www.amybel.be/">https://www.amybel.be/</a>	Associate Member

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

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

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

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

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

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



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



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

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Country/Region	Organisation	Website	Membership
France	Incontinentia Pigmenti France	<a href="http://incontinentia-pigmenti.fr/">http://incontinentia-pigmenti.fr/</a>	Full Member
France	Inflam'Œil	<a href="https://www.inflamoeil.org/">https://www.inflamoeil.org/</a>	Full Member
France	KCNQ2 France Développement	<a href="https://kcnq2francedeveloppement.fr/">https://kcnq2francedeveloppement.fr/</a>	Full Member
France	La Maison 8p	<a href="https://www.lamaison8p.fr">https://www.lamaison8p.fr</a>	Associate Member
France	LAMA2 France, Contre les dystrophies musculaires par déficit en méro	<a href="https://www.lama2.fr/">https://www.lama2.fr/</a>	Full Member
France	Les Amis de Remi	<a href="http://www.lesamideremi.fr">http://www.lesamideremi.fr</a>	Full Member
France	Les Petits Bourdons	<a href="http://www.lespetitsbourdons.org">http://www.lespetitsbourdons.org</a>	Associate Member
France	Lesch-Nyhan Action	<a href="https://www.lesch-nyhan-action.org/">https://www.lesch-nyhan-action.org/</a>	Full Member
France	Let's Cure ACC	<a href="https://lets cureacc.com/">https://lets cureacc.com/</a>	Associate Member
France	LHF Espoir	<a href="https://lhfespoir.org/">https://lhfespoir.org/</a>	Full Member
France	Ligue Nationale Contre Le Cancer	<a href="http://www.ligue-cancer.net">http://www.ligue-cancer.net</a>	Full Member
France	Lupus France	<a href="http://www.lupusfrance.com/">http://www.lupusfrance.com/</a>	Full Member
France	MED13L Syndrome association	<a href="https://www.med13lsyndrome.eu/">https://www.med13lsyndrome.eu/</a>	Associate Member
France	MNT Mon Poumon Mon Air	<a href="https://www.mntmonpoumonmonair.c">https://www.mntmonpoumonmonair.c</a>	Full Member
France	Mosaïques - Association des "X Fragile"	<a href="http://www.xfragile.org">http://www.xfragile.org</a>	Full Member
France	Neuro IFF France et Maladies à Prions	<a href="https://neuroiffrance.my.canva.site/#">https://neuroiffrance.my.canva.site/#</a>	Associate Member
France	Ouvrir Les Yeux	<a href="https://www.ouvrirlesyeux.org/fr/">https://www.ouvrirlesyeux.org/fr/</a>	Full Member
France	Petit Coeur de Beurre	<a href="https://www.petitcoeurdebeurre.fr">https://www.petitcoeurdebeurre.fr</a>	Full Member
France	Pour Nos Enfants H2	<a href="https://pournosenfantsh2.org/">https://pournosenfantsh2.org/</a>	Associate Member
France	Prader Willi France	<a href="https://www.prader-willi.fr/">https://www.prader-willi.fr/</a>	Full Member
France	Retina France	<a href="https://www.retina.fr/">https://www.retina.fr/</a>	Full Member
France	Sanfilippo Sud	<a href="https://www.sanfilippo-sud.com/">https://www.sanfilippo-sud.com/</a>	Full Member
France	SDTB, notre bataille	<a href="https://www.infos-sdtb.fr/fr/">https://www.infos-sdtb.fr/fr/</a>	Full Member
France	Solidarité Handicap autour des Maladies Rares	<a href="http://www.solhand-maladiesrares.org">http://www.solhand-maladiesrares.org</a>	Full Member
France	Tintamarre	<a href="https://www.asso-tintamarre.org/">https://www.asso-tintamarre.org/</a>	Full Member
France	Union Nationale des Associations Parents et Amis Personnes Handicap	<a href="https://www.unapei.org/">https://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 Dunnigan	<a href="https://vaincre-dunnigan.org/">https://vaincre-dunnigan.org/</a>	Associate Member
France	Vaincre la Mucoviscidose	<a href="https://www.vaincrelamuco.org/">https://www.vaincrelamuco.org/</a>	Full Member
France	Vaincre La Papillomatose Respiratoire Récurrente	<a href="http://www.vaincrepr.fr">http://www.vaincrepr.fr</a>	Full Member
France	Vaincre Les Maladies Lysosomales	<a href="http://www.vml-asso.org">http://www.vml-asso.org</a>	Full Member
France	Valentin APAC - Association de Porteurs d'Anomalies Chromosomique	<a href="https://www.valentin-apac.org">https://www.valentin-apac.org</a>	Full Member

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

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

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

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

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India	Organization For Rare Diseases India	<a href="https://ordindia.in/">https://ordindia.in/</a>	Associate Member
Iran (Islamic Republic of)	Rare Disease Foundation of Iran	<a href="http://radoir.org/fa/">http://radoir.org/fa/</a>	Associate Member
Ireland	22Q11 Ireland Support Group	<a href="http://www.22q11ireland.org">http://www.22q11ireland.org</a>	Full Member
Ireland	Alpha One Foundation	<a href="http://www.alpha1.ie">http://www.alpha1.ie</a>	Full Member
Ireland	Barretstown Serious Fun	<a href="http://www.barretstown.org">http://www.barretstown.org</a>	Associate Member
Ireland	Cystic Fibrosis Ireland	<a href="http://www.cfireland.ie">http://www.cfireland.ie</a>	Associate Member
Ireland	Cystinosis Ireland	<a href="http://cystinosis.ie">http://cystinosis.ie</a>	Full Member
Ireland	Cystinosis Support Network Europe	<a href="https://cystinosis-europe.eu/">https://cystinosis-europe.eu/</a>	Associate Member
Ireland	Debra Ireland	<a href="http://www.debraireland.org">http://www.debraireland.org</a>	Full Member
Ireland	European Sick Cell Federation	<a href="https://escfederation.eu/">https://escfederation.eu/</a>	Associate Member
Ireland	Fighting Blindness	<a href="https://www.fightingblindness.ie/">https://www.fightingblindness.ie/</a>	Full Member
Ireland	Friedreich's Ataxia Research Alliance Ireland	<a href="https://faraireland.eu/">https://faraireland.eu/</a>	Full Member
Ireland	Irish Cancer Society	<a href="http://www.cancer.ie">http://www.cancer.ie</a>	Associate Member
Ireland	Irish MPS Society	<a href="http://www.mpsociety.ie/wordpress/">http://www.mpsociety.ie/wordpress/</a>	Full Member
Ireland	Neurofibromatosis Association of Ireland	<a href="http://www.nfaireland.ie">http://www.nfaireland.ie</a>	Full Member
Ireland	Pituitary Foundation Ireland	<a href="https://www.pituitaryireland.ie/">https://www.pituitaryireland.ie/</a>	Full Member
Ireland	Popsycle Foundation	<a href="https://www.facebook.com/Popsycle01">https://www.facebook.com/Popsycle01</a>	Associate Member
Ireland	Rare Diseases Ireland	<a href="http://rdi.ie/">http://rdi.ie/</a>	Full Member
Ireland	Rare Ireland	<a href="https://www.rareireland.ie/">https://www.rareireland.ie/</a>	Associate Member
Ireland	Retina International	<a href="https://retina-international.org/">https://retina-international.org/</a>	Full Member
Ireland	Sickle Cell and Thalassaemia Ireland	<a href="http://www.sicklecellireland.ie">http://www.sicklecellireland.ie</a>	Full Member
Ireland	Spina Bifida & Hydrocephalus Paediatric Advocacy Group	<a href="https://www.sbhpag.com/">https://www.sbhpag.com/</a>	Associate Member
Ireland	The Irish Fragile X Society	<a href="http://fragilexireland.org">http://fragilexireland.org</a>	Full Member
Ireland	TSC Ireland	<a href="https://tscireland.org/">https://tscireland.org/</a>	Full Member
Ireland	Usher syndrome Ireland	<a href="https://usherireland.org/">https://usherireland.org/</a>	Associate Member
Ireland	Vasculitis Ireland Awareness	<a href="https://www.vasculitis-ia.org/">https://www.vasculitis-ia.org/</a>	Full Member
Israel	CdLS Israeli Foundation	<a href="https://www.cdlsisrael.org.il/">https://www.cdlsisrael.org.il/</a>	Associate Member
Israel	Coalition of Rare Diseases in Israel	<a href="https://www.rdisrael.org.il">https://www.rdisrael.org.il</a>	Associate Member
Israel	GRIN Disorders Research Foundation	<a href="http://www.gringn.com/">http://www.gringn.com/</a>	Associate Member
Israel	Israel Adult Polyglucosan Body Disease		Associate Member
Israel	Little Steps Association	<a href="https://www.littlesteps.org.il/">https://www.littlesteps.org.il/</a>	Associate Member
Israel	NPO for promotion of health and cure of OPMD	<a href="https://opmd.health/en/home-page-en">https://opmd.health/en/home-page-en</a>	Associate Member



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Italy	ABC Associazione Bambini Cri Du Chat	<a href="http://www.criduchat.it">http://www.criduchat.it</a>	Full Member
Italy	ACAR Associazione Conto Alla Rovescia	<a href="https://www.acar-aps.org/">https://www.acar-aps.org/</a>	Full Member
Italy	ACMT- Rete per la malattia di Charcot-Marie-Tooth OdV	<a href="http://www.acmt-rete.it">http://www.acmt-rete.it</a>	Full Member
Italy	Acondroplasia - Insieme Per Crescere - Onlus	<a href="http://www.acondroplasiaonlus.com">http://www.acondroplasiaonlus.com</a>	Full Member
Italy	AIBWS ODV	<a href="https://www.aibws.org">https://www.aibws.org</a>	Full Member
Italy	AISAP aps	<a href="https://www.aima-child.it/">https://www.aima-child.it/</a>	Full Member
Italy	Angeli Noonan	<a href="https://www.angelinoonan.it/">https://www.angelinoonan.it/</a>	Full Member
Italy	Aniridia Italiana APS	<a href="http://www.aniridia.it/">http://www.aniridia.it/</a>	Full Member
Italy	APS Bottega del Sorriso	<a href="https://www.apsbottegadelsorriso.it/">https://www.apsbottegadelsorriso.it/</a>	Full Member
Italy	Assi Gulliver - Associazione Sindrome di Sotos Italia	<a href="https://www.assigulliver.it/">https://www.assigulliver.it/</a>	Full Member
Italy	Associaizone Nazionale Pemfigo/Pemfigoide	<a href="https://www.pemfigo.org/">https://www.pemfigo.org/</a>	Full Member
Italy	Associazione ESEO Italia APS	<a href="https://www.eseoitalia.it/">https://www.eseoitalia.it/</a>	Full Member
Italy	Associazione Famiglie COL4A1-A2 APS	<a href="http://www.col4a1.it/">http://www.col4a1.it/</a>	Full Member
Italy	Associazione Famiglie di Soggetti con Deficit dell'Ormone della Crescita	<a href="http://www.afadoc.it">http://www.afadoc.it</a>	Full Member
Italy	Associazione HHT Onilde Carini APS	<a href="https://www.hht.it/">https://www.hht.it/</a>	Full Member
Italy	Associazione Italiana Adrenoleucodistrofia Onlus	<a href="https://www.adrenoleucodistrofia.it/">https://www.adrenoleucodistrofia.it/</a>	Associate Member
Italy	Associazione Italiana Cistite Interstiziale	<a href="http://www.aici-onlus.it">http://www.aici-onlus.it</a>	Full Member
Italy	Associazione Italiana Dei Cardiopatici Congeniti Adulti - Italian Guch As	<a href="http://www.aicca.eu">http://www.aicca.eu</a>	Associate Member
Italy	Associazione Italiana Estrofia Vescicale-Epispadia ODV	<a href="http://www.estrofiavescicale.it">http://www.estrofiavescicale.it</a>	Full Member
Italy	Associazione Italiana Gaucher ODV	<a href="http://www.gaucheritalia.org">http://www.gaucheritalia.org</a>	Full Member
Italy	Associazione Italiana Glicogenosi	<a href="http://www.aig-aig.it">http://www.aig-aig.it</a>	Full Member
Italy	Associazione Italiana Laryngectomizzati	<a href="http://www.ailar.it">http://www.ailar.it</a>	Associate Member
Italy	Associazione Italiana Leucodistrofie Unite	<a href="http://digilander.libero.it/ailu/">http://digilander.libero.it/ailu/</a>	Full Member
Italy	Associazione Italiana Linfoistiocitosi Emofagocitica	<a href="https://www.aileonlus.org/">https://www.aileonlus.org/</a>	Associate Member
Italy	Associazione Italiana Malati di Alcaptonuria	<a href="https://www.aimaku.it">https://www.aimaku.it</a>	Full Member
Italy	Associazione Italiana Miastenia e Malattie Immunodegenerative - Ami	<a href="http://www.miastenia.it">http://www.miastenia.it</a>	Full Member
Italy	Associazione Italiana Miastenia Onlus	<a href="http://www.viverelamiastenia.it">http://www.viverelamiastenia.it</a>	Full Member
Italy	Associazione Italiana Morbo di Hirschsprung	<a href="http://amorhi.org">http://amorhi.org</a>	Associate Member
Italy	Associazione Italiana Mucopolisaccaridosi e Malattie Affini	<a href="http://www.aimps.it">http://www.aimps.it</a>	Full Member
Italy	Associazione Italiana Niemann Pick Onlus	<a href="http://www.niemannpick.org">http://www.niemannpick.org</a>	Full Member
Italy	Associazione Italiana Osteogenesi Imperfetta	<a href="https://www.asitoi.org/">https://www.asitoi.org/</a>	Full Member
Italy	Associazione Italiana per la lotta alle PHTS	<a href="http://www.ptenitalia.org">http://www.ptenitalia.org</a>	Full Member

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

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

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

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Country/Region	Organisation	Website	Membership
Morocco	Sun'Hop		Associate Member
Nepal	GBS/CIDP Foundation Nepal		Associate Member
Nepal	Muscular Dystrophy Organization Nepal	<a href="https://www.facebook.com/MuscularD">https://www.facebook.com/MuscularD</a>	Associate Member
Netherlands	A Different Story	<a href="https://adifferentstory.nl/">https://adifferentstory.nl/</a>	Associate Member
Netherlands	AA Foundation & PNH Contact Group	<a href="http://www.aaenpnh.nl">http://www.aaenpnh.nl</a>	Full Member
Netherlands	Acanthamoeba Keratitis Eye Foundation	<a href="https://akeyefoundation.com/">https://akeyefoundation.com/</a>	Associate Member
Netherlands	ALS patiëntenvereniging (ALS Patient Association)	<a href="https://www.alspatientenvereniging.nl">https://www.alspatientenvereniging.nl</a>	Full Member
Netherlands	Amyloidose Nederland	<a href="http://amyloidose.nl">http://amyloidose.nl</a>	Full Member
Netherlands	Angelman Syndrome Alliance	<a href="https://angelmanalliance.org/">https://angelmanalliance.org/</a>	Full Member
Netherlands	Ataxie Vereniging Nederland	<a href="https://ataxie.nl/">https://ataxie.nl/</a>	Full Member
Netherlands	Bijnierverseniging (Dutch Adrenal Patient Society)	<a href="http://www.nvacp.nl">http://www.nvacp.nl</a>	Full Member
Netherlands	Childhood Cancer International	<a href="https://www.childhoodcancerinternational.org/">https://www.childhoodcancerinternational.org/</a>	Full Member
Netherlands	Chordoma Foundation Europe	<a href="https://nl.chordomafoundation.org/">https://nl.chordomafoundation.org/</a>	Full Member
Netherlands	CMTC-OVM	<a href="http://www.cmtc.nl">http://www.cmtc.nl</a>	Full Member
Netherlands	Cornelia de Lange Syndrome World Federation	<a href="http://www.cdlsworld.org">http://www.cdlsworld.org</a>	Full Member
Netherlands	Cure ADOA Foundation	<a href="https://adoa.eu/">https://adoa.eu/</a>	Full Member
Netherlands	European Cleft Organisation	<a href="http://europeancleft.org/">http://europeancleft.org/</a>	Associate Member
Netherlands	European Society for Phenylketonuria	<a href="http://www.espk.org">http://www.espk.org</a>	Associate Member
Netherlands	Eurosarcoidosis Research Fund	<a href="https://sarcoidosis.eu/">https://sarcoidosis.eu/</a>	Associate Member
Netherlands	Fabry Support & Informatie Groep Nederland	<a href="https://fabry.nl/">https://fabry.nl/</a>	Full Member
Netherlands	FH Europe Foundation	<a href="https://www.fheurope.org/">https://www.fheurope.org/</a>	Associate Member
Netherlands	Fibrodysplasia Ossificans Progressiva Stichting Nederland	<a href="https://fopstichting.nl/">https://fopstichting.nl/</a>	Full Member
Netherlands	FSHD Europe	<a href="http://fshd-europe.info">http://fshd-europe.info</a>	Full Member
Netherlands	Hevas	<a href="https://www.hevas.eu/">https://www.hevas.eu/</a>	Full Member
Netherlands	International Mito Patients	<a href="https://mitopatients.org/">https://mitopatients.org/</a>	Full Member
Netherlands	International Painful Bladder Foundation	<a href="https://www.painful-bladder.org/">https://www.painful-bladder.org/</a>	Associate Member
Netherlands	International Porphyria Patient Network	<a href="https://porphyria.network/IPPN/">https://porphyria.network/IPPN/</a>	Associate Member
Netherlands	Interstitiële Cystitis Patiëntenvereniging	<a href="http://www.icpatienten.nl">http://www.icpatienten.nl</a>	Full Member
Netherlands	KAISZ - Children with a Autoimmunity or Autoinflammatory Disease	<a href="http://www.kaisz.nl">http://www.kaisz.nl</a>	Full Member
Netherlands	LMNA Cardiac Foundation	<a href="https://www.lmnacardiac.org/">https://www.lmnacardiac.org/</a>	Associate Member
Netherlands	MSS (Marshall-Smith Syndrome) Research Foundation	<a href="https://marshallsmith.org/">https://marshallsmith.org/</a>	Full Member
Netherlands	Naevus Global	<a href="https://naevusglobal.nevusnetwerk.nl/">https://naevusglobal.nevusnetwerk.nl/</a>	Associate Member

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Netherlands	National Association ReumaZorg Nederland	<a href="https://reumazorgnederland.nl/">https://reumazorgnederland.nl/</a>	Associate Member
Netherlands	Nationale Vereniging L.E. patiënten	<a href="http://www.nvle.org/">http://www.nvle.org/</a>	Full Member
Netherlands	Nederlands Netwerk voor Lymfoedeem en Lipoedeem	<a href="https://lymfoedeem.nl/">https://lymfoedeem.nl/</a>	Associate Member
Netherlands	Nederlandse Hypofyse Stichting (Dutch Pituitary Foundation)	<a href="http://www.hypofyse.nl">http://www.hypofyse.nl</a>	Full Member
Netherlands	Nederlandse Leverpatienten Vereniging	<a href="http://www.leverpatientenvereniging.r">http://www.leverpatientenvereniging.r</a>	Full Member
Netherlands	Nederlandse Phenylketonurie Vereniging / Dutch PKU Association	<a href="https://www.pkuvereniging.nl/">https://www.pkuvereniging.nl/</a>	Full Member
Netherlands	Nederlandse Vereniging van Hemofilie-Patiënten/Netherlands Haemoph	<a href="http://www.nvhp.nl">http://www.nvhp.nl</a>	Full Member
Netherlands	Nephceurope	<a href="http://nephceurope.eu/nc/">http://nephceurope.eu/nc/</a>	Associate Member
Netherlands	Neurofibromatose Vereniging Nederland	<a href="http://www.neurofibromatose.nl">http://www.neurofibromatose.nl</a>	Full Member
Netherlands	Nevus Netwerk Nederland	<a href="https://nevusnetwerk.nl/">https://nevusnetwerk.nl/</a>	Full Member
Netherlands	NF Patients United	<a href="https://www.nf-patients.eu/">https://www.nf-patients.eu/</a>	Associate Member
Netherlands	Oscar Nederland	<a href="https://oscarnederland.nl/">https://oscarnederland.nl/</a>	Full Member
Netherlands	Patientenorganisatie Fibreuze Dysplasie	<a href="http://www.fibreuzedysplasie.eu">http://www.fibreuzedysplasie.eu</a>	Full Member
Netherlands	Patiëntenvereniging voor Blaasextrofie Nederland	<a href="https://blaasextrofie.nl/">https://blaasextrofie.nl/</a>	Full Member
Netherlands	Sarcoidose.Nl	<a href="http://www.sarcoidose.nl">http://www.sarcoidose.nl</a>	Full Member
Netherlands	Spierziekten Nederland - Dutch Neuromuscular Patient Association	<a href="http://www.vsn.nl">http://www.vsn.nl</a>	Full Member
Netherlands	Stichting Hart4Onderzoek / Heart4Research	<a href="https://hart4onderzoek.nl/">https://hart4onderzoek.nl/</a>	Full Member
Netherlands	Stichting Histiocytose Nederland	<a href="https://www.histio.nl/">https://www.histio.nl/</a>	Full Member
Netherlands	Stichting Huidlymfoom (Dutch Cutaneous Lymphoma Foundation).	<a href="https://stichtinghuidlymfoom.nl">https://stichtinghuidlymfoom.nl</a>	Full Member
Netherlands	Stichting IJzersterk	<a href="http://www.stichtingijzersterk.nl">http://www.stichtingijzersterk.nl</a>	Associate Member
Netherlands	Stichting Kans voor PKAN Kinderen	<a href="https://kansvoorpkankinderen.nl">https://kansvoorpkankinderen.nl</a>	Full Member
Netherlands	Stichting Overdruksyndroom NL	<a href="https://sosnl.nl">https://sosnl.nl</a>	Full Member
Netherlands	Stichting Pierre Robin Europe - Pierre Robin Europe Foundation	<a href="http://pierrerobineurope.com">http://pierrerobineurope.com</a>	Full Member
Netherlands	Stichting RPF Nederland / Dutch RPF Foundation	<a href="https://rpf.nl/">https://rpf.nl/</a>	Full Member
Netherlands	Stichting Shwachman Diamond Syndrome Support Holland	<a href="http://www.shwachman.nl">http://www.shwachman.nl</a>	Full Member
Netherlands	Stichting Spierkracht	<a href="https://stichtingspierkrac.wixsite.com/">https://stichtingspierkrac.wixsite.com/</a>	Associate Member
Netherlands	Stichting SynGAP Research Fund Europe	<a href="https://www.syngapresearchfund.org/">https://www.syngapresearchfund.org/</a>	Full Member
Netherlands	Stichting TAPS Support/ TAPS Support Foundation	<a href="https://www.stichtingtapssupport.com">https://www.stichtingtapssupport.com</a>	Associate Member
Netherlands	Stichting Terre - Rett Syndrome Foundation	<a href="https://stichtingterre.nl/">https://stichtingterre.nl/</a>	Full Member
Netherlands	Stichting voor Afweerstoornissen	<a href="https://stichtingvoorafweerstoornissen">https://stichtingvoorafweerstoornissen</a>	Full Member
Netherlands	Stichting Zeldzame Bloedziekten	<a href="http://www.bloedziekten.nl">http://www.bloedziekten.nl</a>	Associate Member
Netherlands	Thyroid Cancer Alliance	<a href="https://www.facebook.com/ThyroidCa">https://www.facebook.com/ThyroidCa</a>	Full Member

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Country/Region	Organisation	Website	Membership
Netherlands	Vasculitis Stichting	<a href="http://www.vasculitis.nl">http://www.vasculitis.nl</a>	Full Member
Netherlands	Vereniging van Ehlers Danlos Patienten	<a href="https://ehlers-danlos.nl/">https://ehlers-danlos.nl/</a>	Full Member
Netherlands	Vereniging voor Ichthyosis Netwerken	<a href="https://ichthyosisnetwerken.nl/">https://ichthyosisnetwerken.nl/</a>	Full Member
Netherlands	VHL Europa	<a href="https://www.vhl-europa.org/">https://www.vhl-europa.org/</a>	Associate Member
Netherlands	Volwassenen, Kinderen En Stofwisselingsziekten	<a href="https://www.stofwisselingsziekten.nl/">https://www.stofwisselingsziekten.nl/</a>	Full Member
Netherlands	VSOP - Vereniging Samenwerkende Ouder En Patiëntenorganisaties	<a href="https://vsop.nl/">https://vsop.nl/</a>	Full Member
Netherlands	World Alliance of Pituitary Organizations	<a href="http://www.wapo.org">http://www.wapo.org</a>	Associate Member
Netherlands	World Duchenne Organization	<a href="https://www.worldduchenne.org/">https://www.worldduchenne.org/</a>	Full Member
New Zealand	Rare Disorders NZ	<a href="http://www.nzord.org.nz">http://www.nzord.org.nz</a>	Associate Member
North Macedonia	APRDD My rare world		Associate Member
North Macedonia	Association for help and support of patients and their caregivers with I	<a href="http://www.hema.org.mk">http://www.hema.org.mk</a>	Associate Member
North Macedonia	FEMINA M Skopje	<a href="http://www.feminam.org.mk/">http://www.feminam.org.mk/</a>	Associate Member
North Macedonia	Life With Challenges	<a href="http://challenges.mk/?p=2288&amp;lang=en">http://challenges.mk/?p=2288&amp;lang=en</a>	Full Member
North Macedonia	National Alliance For Rare Diseases of North Macedonia		Full Member
North Macedonia	Save Liver Association of Patients with Liver Diseases	<a href="https://www.facebook.com/udrugaslaç">https://www.facebook.com/udrugaslaç</a>	Full Member
North Macedonia	Stop SMA Macedonia	<a href="https://www.facebook.com/STOP-SMA">https://www.facebook.com/STOP-SMA</a>	Associate Member
Norway	Aniridia Europe	<a href="http://www.aniridia.eu">http://www.aniridia.eu</a>	Full Member
Norway	European Huntington Association	<a href="http://eurohuntington.org/">http://eurohuntington.org/</a>	Full Member
Norway	Frambu - Resource Centre For Rare Disorders	<a href="https://frambu.no/">https://frambu.no/</a>	Full Member
Norway	HHT-Osler foreningen, Norge	<a href="http://www.osler.no">http://www.osler.no</a>	Full Member
Norway	Hjernesvulstforeningen (Norwegian Brain Tumour Association)	<a href="https://hjernesvulst.no/">https://hjernesvulst.no/</a>	Full Member
Norway	Hypopara Norge	<a href="https://www.hypopara.no/">https://www.hypopara.no/</a>	Full Member
Norway	International Huntington Association	<a href="https://huntington-disease.org/">https://huntington-disease.org/</a>	Associate Member
Norway	MPS-Foreningen I Norge	<a href="http://mpsforeningen.no/">http://mpsforeningen.no/</a>	Associate Member
Norway	Norsk Forening for Ehlers-Danlos Syndrom	<a href="https://www.eds-foreningen.no/">https://www.eds-foreningen.no/</a>	Full Member
Norway	Norsk Forening for Osteogenesis Imperfecta/The Norwegian Osteogen	<a href="https://nfoi.no/">https://nfoi.no/</a>	Full Member
Norway	Norsk Forening For Tuberos Sklerose	<a href="http://www.nfts.no">http://www.nfts.no</a>	Full Member
Norway	Norwegian Federation of Organisations of Disabled People (Funksjonsl	<a href="https://www.ffe.no/">https://www.ffe.no/</a>	Full Member
Norway	Norwegian organisation for Prader Willis syndrome	<a href="https://www.prader-willis.no/">https://www.prader-willis.no/</a>	Full Member
Poland	3majmy sie razem - Let's get together	<a href="https://3majmysierazem.pl/">https://3majmysierazem.pl/</a>	Associate Member
Poland	AGO Alliance Poland	<a href="https://www.agoresearch.org/">https://www.agoresearch.org/</a>	Associate Member
Poland	Association for people with severe refractory epilepsy DRAVET.PL	<a href="http://www.dravet.pl/">http://www.dravet.pl/</a>	Full Member



## EURODIS Members - May 2025

Country/Region	Organisation	Website	Membership
Poland	Association of Families with Angelman Syndrome in Poland	<a href="https://www.zespolangelmana.org/">https://www.zespolangelmana.org/</a>	Associate Member
Poland	Debra Polska	<a href="http://www.debra-kd.pl/">http://www.debra-kd.pl/</a>	Full Member
Poland	FAST Poland	<a href="https://www.cureangelman.pl/">https://www.cureangelman.pl/</a>	Associate Member
Poland	Foundation for Leukemia Patients / Fundacji Na Rzecz Pomocy Chorym	<a href="https://fundacja.hematologiczna.org/">https://fundacja.hematologiczna.org/</a>	Associate Member
Poland	Foundation of Borys the Hero /Fundacja Bohatera Borysa	<a href="http://bohaterborys.pl/">http://bohaterborys.pl/</a>	Full Member
Poland	Fundacja Celując w Przyszłość / Aiming for the future Foundation	<a href="https://celujacwprzyszlosc.org/en">https://celujacwprzyszlosc.org/en</a>	Associate Member
Poland	Fundacja Jesteśmy Pod Scianą / Foundation We Are Against the Wall	<a href="https://jestesmypodsciana.pl/">https://jestesmypodsciana.pl/</a>	Full Member
Poland	Fundacja Lelka /Lelek Foundation	<a href="https://fundacjalelka.pl/">https://fundacjalelka.pl/</a>	Full Member
Poland	Fundacja Sanfilippo	<a href="http://sanfilippo.org.pl/en/home/">http://sanfilippo.org.pl/en/home/</a>	Associate Member
Poland	Fundacja SMA (SMA Foundation Poland)	<a href="http://www.fsma.pl">http://www.fsma.pl</a>	Full Member
Poland	Fundacja Umieć Pomagać (Foundation For RD MPS )	<a href="http://www.umiecpomagac.org">http://www.umiecpomagac.org</a>	Full Member
Poland	Krajowe Forum Orphan/National Forum Orphan	<a href="http://rzadkiechoroby.org/">http://rzadkiechoroby.org/</a>	Full Member
Poland	Matio Fundacji Pomocy Rodzinom I Chorym Na Mukowiscydozę/MATI	<a href="http://www.mukowiscydoza.pl">http://www.mukowiscydoza.pl</a>	Full Member
Poland	PACS2 Research Foundation	<a href="https://www.pacs2research.org/">https://www.pacs2research.org/</a>	Full Member
Poland	Polish PKU and RD Association "Ars Vivendi"	<a href="http://www.fenylketonuria.org">http://www.fenylketonuria.org</a>	Full Member
Poland	Polish Society of MPS and Related Diseases	<a href="https://choroby rzadkie.pl/">https://choroby rzadkie.pl/</a>	Full Member
Poland	Polskie Stowarzyszenie Na Rzecz Osób Z AHC	<a href="http://www.stow.ahc-pl.org/">http://www.stow.ahc-pl.org/</a>	Associate Member
Poland	Polskie Stowarzyszenie Rodzin z Atrezią Przewodzenia / Polish Association c	<a href="https://przelyczki.org.pl/">https://przelyczki.org.pl/</a>	Associate Member
Poland	Rett Syndrome Poland - Ogólnopolskie Stowarzyszenie Pomocy Osob	<a href="https://rettsyndrome.pl/">https://rettsyndrome.pl/</a>	Full Member
Poland	Stowarzyszenie Rodzin STXBP1	<a href="https://stxbp1.pl/">https://stxbp1.pl/</a>	Full Member
Poland	The Dina Radziwillowa Child's Heart Foundation	<a href="https://www.sercedziecka.org.pl/">https://www.sercedziecka.org.pl/</a>	Full Member
Portugal	andLINFA   Associação Nacional de Doentes Linfáticos / National Associ	<a href="https://andlinfa.pt/">https://andlinfa.pt/</a>	Full Member
Portugal	Associação Nacional De Displasias Ósseas	<a href="http://www.andoportugal.org">http://www.andoportugal.org</a>	Associate Member
Portugal	Associação Nacional para Divulgar e Orientar para Combater e Enfrent	<a href="http://doce.pt/wp/">http://doce.pt/wp/</a>	Associate Member
Portugal	Associação Portuguesa CDG e Outras Doenças Metabólicas	<a href="https://www.facebook.com/SINDROME">https://www.facebook.com/SINDROME</a>	Associate Member
Portugal	Associação Portuguesa De Charcot-Marie-Tooth	<a href="https://www.facebook.com/associacao">https://www.facebook.com/associacao</a>	Full Member
Portugal	Associação Portuguesa De Insuficientes Renais	<a href="http://www.apir.org.pt">http://www.apir.org.pt</a>	Full Member
Portugal	Associação Portuguesa de Leucemias e Linfomas	<a href="http://www.apll.org">http://www.apll.org</a>	Full Member
Portugal	Associação Portuguesa De Neuromusculares	<a href="https://apn.pt/apn/">https://apn.pt/apn/</a>	Full Member
Portugal	Associação Portuguesa de Osteogénese Imperfeita	<a href="http://www.apoi.pt">http://www.apoi.pt</a>	Full Member
Portugal	Associação Sanfilippo Portugal	<a href="http://www.sanfilippoportugal.com">http://www.sanfilippoportugal.com</a>	Full Member
Portugal	EVITA	<a href="http://www.evita cancro.org/">http://www.evita cancro.org/</a>	Associate Member

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Country/Region	Organisation	Website	Membership
Portugal	Fedra - Federação Portuguesa De Doenças Raras	<a href="http://www.fedra.pt">http://www.fedra.pt</a>	Associate Member
Portugal	Liga Portuguesa contra as Doenças Reumáticas	<a href="http://www.lpcdr.org.pt">http://www.lpcdr.org.pt</a>	Full Member
Portugal	Oncological and Gynaecological Movement	<a href="https://mogportugal.pt/">https://mogportugal.pt/</a>	Associate Member
Portugal	Raramente	<a href="https://raramente.org/en/">https://raramente.org/en/</a>	Associate Member
Portugal	Rarissimas - Associacao Nacional De Deficiencias Mentais E Raras	<a href="https://rarissimas.pt/">https://rarissimas.pt/</a>	Full Member
Portugal	RD-Portugal - União de Associações das Doenças Raras de Portugal	<a href="https://raras.pt/">https://raras.pt/</a>	Associate Member
Republic of Moldova	AO SOS Autism	<a href="https://autismmoldova.md/">https://autismmoldova.md/</a>	Associate Member
Republic of Moldova	Copiii Ploii	<a href="https://www.facebook.com/AO-Copiii-1">https://www.facebook.com/AO-Copiii-1</a>	Full Member
Romania	Asociatia Copilul Meu-Inima Mea	<a href="http://www.acmim.ro">http://www.acmim.ro</a>	Full Member
Romania	Asociatia Nationala Miastenia Gravis Romania /Romanian Myasthenia	<a href="http://www.miastenie.ro">http://www.miastenie.ro</a>	Full Member
Romania	Asociatia Pentru Matei	<a href="https://www.pentrumatei.ro/">https://www.pentrumatei.ro/</a>	Full Member
Romania	Asociatia Persoanelor Cu Glicogenoza (APG Romania)	<a href="https://glicogenoza.ro/">https://glicogenoza.ro/</a>	Associate Member
Romania	Asociația Română De Cancere Rar/ Romanian Association for Rare Can	<a href="http://www.arcrareromania.ro">http://www.arcrareromania.ro</a>	Associate Member
Romania	Asociatia Romana pentru Boli Neurologice Periferice/Romanian Associ	<a href="https://arbnp-cidp.ro/">https://arbnp-cidp.ro/</a>	Full Member
Romania	Asociatia Romana Spina Bifida si Hidrocefalie	<a href="https://www.facebook.com/ARSBH/">https://www.facebook.com/ARSBH/</a>	Associate Member
Romania	Asociatia Sindromul Coffin-Lowry/Coffin-Lowry Syndrome Association	<a href="http://www.coffin-lowry.ro/">http://www.coffin-lowry.ro/</a>	Associate Member
Romania	Asociatia Smacare	<a href="http://www.amiotrofie-spinala.ro">http://www.amiotrofie-spinala.ro</a>	Full Member
Romania	Asociatia Werdnig Hoffman Awh	<a href="https://www.facebook.com/werdnigho">https://www.facebook.com/werdnigho</a>	Full Member
Romania	Autoimmune Diseases Patients Association	<a href="http://www.apaa.ro">http://www.apaa.ro</a>	Associate Member
Romania	Charcot Marie Tooth Romania Association	<a href="http://www.asociatiacmt.ro">http://www.asociatiacmt.ro</a>	Associate Member
Romania	DMD Care	<a href="https://dmdcare.org">https://dmdcare.org</a>	Full Member
Romania	Mastocytosis Support Association Romania	<a href="http://www.mastocitoza.ro">http://www.mastocitoza.ro</a>	Associate Member
Romania	Neuro Move CMT Association	<a href="https://neuromovecmt.ro/">https://neuromovecmt.ro/</a>	Associate Member
Romania	Romanian National Alliance for Rare Diseases	<a href="https://bolirareromania.ro/">https://bolirareromania.ro/</a>	Full Member
Romania	Romanian Prader Willi Association	<a href="http://www.apwromania.ro">http://www.apwromania.ro</a>	Full Member
Russian Federation	Help to Cystic Fibrosis Patients		Full Member
Russian Federation	Interregional Public Organisation For Gaucher Disease	<a href="https://www.gaucher.ru/">https://www.gaucher.ru/</a>	Full Member
Russian Federation	Interregional Public Organisation of Patients with Fabry Disease "The R	<a href="https://ufafabry.ru/">https://ufafabry.ru/</a>	Full Member
Russian Federation	Inter-Regional Support Centre for Patients with Aniridia " Iris"	<a href="https://aniridia.ru/">https://aniridia.ru/</a>	Associate Member
Russian Federation	Look to see	<a href="https://looktosee.ru/">https://looktosee.ru/</a>	Full Member
Russian Federation	MPS Russia	<a href="http://www.mps-russia.org">http://www.mps-russia.org</a>	Full Member
Russian Federation	National Association of Organization of Patient with Rare Diseases "Ge	<a href="https://nacgenetic.ru/">https://nacgenetic.ru/</a>	Associate Member

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Country/Region	Organisation	Website	Membership
Russian Federation	NGO "Fragile Children"	<a href="https://osteogenez.ru/">https://osteogenez.ru/</a>	Full Member
Russian Federation	Russian Association of Rare Diseases	<a href="https://www.rare-diseases.ru/">https://www.rare-diseases.ru/</a>	Full Member
Russian Federation	Russian Patient Association	<a href="https://vspru.ru/en">https://vspru.ru/en</a>	Associate Member
Russian Federation	Russian Rett Syndrome Asociation	<a href="https://radugaclinic.ru/">https://radugaclinic.ru/</a>	Associate Member
Russian Federation	SPIPORZ Union of patients with rare diseases and rare disease patients	<a href="https://spiporz.ru/">https://spiporz.ru/</a>	Associate Member
Russian Federation	The Association of Primary Immunodeficiency Patients	<a href="https://www.oppid.ru/">https://www.oppid.ru/</a>	Full Member
Rwanda	Centre Alliance for Rare Diseases	<a href="https://centre-alliance.rw/">https://centre-alliance.rw/</a>	Associate Member
Serbia	Child Rare Disease Support and Research Association Life	<a href="http://www.zivotorg.org">http://www.zivotorg.org</a>	Associate Member
Serbia	Citizens Association "Bromologos"	<a href="https://fenilketonurija.com/">https://fenilketonurija.com/</a>	Associate Member
Serbia	DMD Serbia	<a href="http://dmdsrbija.rs/">http://dmdsrbija.rs/</a>	Full Member
Serbia	Lil' Brave One (Hrabrisa )	<a href="https://www.hrabrisa.rs/en">https://www.hrabrisa.rs/en</a>	Full Member
Serbia	Lymphoma Patients' Association	<a href="http://www.lipa.org.rs">http://www.lipa.org.rs</a>	Associate Member
Serbia	National Organization For Rare Diseases of Serbia	<a href="http://www.norbs.rs">http://www.norbs.rs</a>	Full Member
Singapore	Rare Disorders Society (Singapore)	<a href="https://rdss.org.sg/">https://rdss.org.sg/</a>	Associate Member
Slovakia	Debra SR	<a href="http://www.debra-slovakia.org">http://www.debra-slovakia.org</a>	Full Member
Slovakia	Organisation of Muscular Dystrophy in the Slovak Republic/Organizáci	<a href="http://www.omdvsr.sk/">http://www.omdvsr.sk/</a>	Full Member
Slovakia	Slovak Alliance of Rare Diseases	<a href="http://www.sazch.sk">http://www.sazch.sk</a>	Full Member
Slovakia	Slovak Cystic Fibrosis Association	<a href="https://www.cfasociacia.sk/">https://www.cfasociacia.sk/</a>	Full Member
Slovakia	Zdruzenie Ojedlinelych Genetickych Ochorení	<a href="http://www.zogo.sk/">http://www.zogo.sk/</a>	Associate Member
Slovenia	Association of Patients with Rare Eye Diseases Svetloba	<a href="https://drustvosvetloba.si/">https://drustvosvetloba.si/</a>	Full Member
Slovenia	Debra Slovenia - Drustvo Debra Slovenija	<a href="https://debra-slovenia.si/">https://debra-slovenia.si/</a>	Full Member
Slovenia	Drustvo bolnikov s krvnimi boleznimi Slovenije/Association of Patients	<a href="http://www.drustvo-bkb.si">http://www.drustvo-bkb.si</a>	Full Member
Slovenia	EAMDA - European Alliance of Neuromuscular Disorders Associations	<a href="http://www.eamda.eu/">http://www.eamda.eu/</a>	Full Member
Slovenia	European Foundation for SATB2-Associated Syndrome (SATB2 Europe)	<a href="https://www.satb2europe.org/">https://www.satb2europe.org/</a>	Associate Member
Slovenia	Fabry Patients Association Slovenia / Društvo Bolnikov S Fabryjevo Bol	<a href="http://www.sb-sg.si">http://www.sb-sg.si</a>	Full Member
Slovenia	Foundation of Child Neurology	<a href="http://pednevro.pedkl.si/ustanova/fou">http://pednevro.pedkl.si/ustanova/fou</a>	Associate Member
Slovenia	IDefine Europe - Foundation for the Advanced Treatment of Rare Gene	<a href="https://idefine-europe.org/">https://idefine-europe.org/</a>	Associate Member
Slovenia	Vesele nogice (Happy Feet)	<a href="http://drustvo-veselenogice.si/">http://drustvo-veselenogice.si/</a>	Associate Member
Slovenia	Viljem Julijan Association for Children with Rare Diseases	<a href="http://viljem-julijan.si/">http://viljem-julijan.si/</a>	Full Member
Slovenia	Zavod Bernardi Ventrella	<a href="https://www.zavodbv.org/">https://www.zavodbv.org/</a>	Associate Member
South Africa	Primary Immunodeficiency Network of South Africa	<a href="https://pinsa.org.za/">https://pinsa.org.za/</a>	Associate Member
South Africa	Rare Diseases South Africa NPC	<a href="https://www.rarediseases.co.za/">https://www.rarediseases.co.za/</a>	Associate Member

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Country/Region	Organisation	Website	Membership
Spain	Acción y Cura Para Tay-Sachs	<a href="https://madreperla.org">https://madreperla.org</a>	Full Member
Spain	AHUCE - Asociación Nacional Huesos de Cristal	<a href="http://www.ahuce.org">http://www.ahuce.org</a>	Full Member
Spain	Alianza Española de Familias de von Hippel Lindau	<a href="http://www.alianzavhl.org">http://www.alianzavhl.org</a>	Full Member
Spain	AMAL Asociacion Madrilená de Afectados de Linfedema y Lipedema	<a href="https://www.amalmadrid.com/">https://www.amalmadrid.com/</a>	Full Member
Spain	AMC - Artrogriposis Múltiple Congénita - España	<a href="https://artrogriposis.org/">https://artrogriposis.org/</a>	Full Member
Spain	ASMD España	<a href="https://www.asmd.es/">https://www.asmd.es/</a>	Full Member
Spain	Asociació Catalana de las Neurofibromatosis	<a href="http://www.acnefi.com/castella/gamhc">http://www.acnefi.com/castella/gamhc</a>	Full Member
Spain	Asociacion Albi España	<a href="http://www.asociacionalbi.com/">http://www.asociacionalbi.com/</a>	Full Member
Spain	Asociacion Andaluza de Fibrosis Quística	<a href="http://fqandalucia.org/">http://fqandalucia.org/</a>	Full Member
Spain	Asociación Andaluza de pacientes con Síndrome de Tourette y Trastor	<a href="http://www.tourette.es">http://www.tourette.es</a>	Full Member
Spain	Asociación Atrofia del Nervio Optico de Leber	<a href="https://www.asanol.com/">https://www.asanol.com/</a>	Full Member
Spain	Asociación Chiari y Siringomielia del Principado de Asturias	<a href="http://www.chyspa.org">http://www.chyspa.org</a>	Full Member
Spain	Asociación Ciudadana de Afectados de Cistitis Intersticial	<a href="https://www.acaci.es/">https://www.acaci.es/</a>	Full Member
Spain	Asociación de Acondroplasia y otras Displasias Esqueléticas con Enanias	<a href="https://adee.es/">https://adee.es/</a>	Full Member
Spain	Asociación de Afectados CDKL5	<a href="https://aacdkl5.org">https://aacdkl5.org</a>	Full Member
Spain	Asociación de Afectados de Neurofibromatosis	<a href="http://www.neurofibromatosis.es">http://www.neurofibromatosis.es</a>	Full Member
Spain	Asociación de Afectados por Displasia Ectodérmica	<a href="https://displasiaectodermica.org/">https://displasiaectodermica.org/</a>	Full Member
Spain	Asociacion De Enfermedades Raras D'genes	<a href="http://www.dgenes.es/">http://www.dgenes.es/</a>	Full Member
Spain	Asociación de Epidermolisis Bullosa de España (Debra Spain)	<a href="http://www.pieldemariposa.es">http://www.pieldemariposa.es</a>	Full Member
Spain	Asociación de Esclerodermia Castellon	<a href="https://www.esclerodermia.es/">https://www.esclerodermia.es/</a>	Full Member
Spain	Asociación de Familiares y Afectados por Lipodistrofias	<a href="http://www.aelip.org">http://www.aelip.org</a>	Full Member
Spain	Asociación de Hemoglobinuria Paroxística Nocturna	<a href="https://hpne.es/">https://hpne.es/</a>	Associate Member
Spain	Asociación de Nevus Gigante Congénito	<a href="http://asonevus.org/">http://asonevus.org/</a>	Full Member
Spain	Asociación de Sarcomas Grupo Asistencial	<a href="https://www.asarga.es/">https://www.asarga.es/</a>	Full Member
Spain	Asociación de Síndrome de Lamb-Shaffer España	<a href="https://www.lambShaffer.es">https://www.lambShaffer.es</a>	Associate Member
Spain	Asociación de Uveítis - AUVEA	<a href="https://www.asociacionauvea.es/">https://www.asociacionauvea.es/</a>	Full Member
Spain	Asociación Enfermedad de Kawasaki	<a href="https://asenkawa.org/">https://asenkawa.org/</a>	Full Member
Spain	Asociación Española Aniridia	<a href="http://www.aniridia.es">http://www.aniridia.es</a>	Full Member
Spain	Asociación Española de Amiloidosis	<a href="https://www.amilo.es/">https://www.amilo.es/</a>	Associate Member
Spain	Asociación Española de Angioedema Familiar por Deficiencia del C1-In	<a href="https://www.angioedema-aedaf.org">https://www.angioedema-aedaf.org</a>	Full Member
Spain	Asociación Española de Enfermos de Glucogenosis	<a href="https://www.glucogenosis.org/">https://www.glucogenosis.org/</a>	Full Member
Spain	Asociación Española de Enfermos de Pompe	<a href="http://www.asociaciondepompe.org">http://www.asociaciondepompe.org</a>	Associate Member

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Country/Region	Organisation	Website	Membership
Spain	Asociación Española de Enfermos y Familiares de la Enfermedad de Ga	<a href="https://aeefegaucher.es/">https://aeefegaucher.es/</a>	Full Member
Spain	Asociación Española de Esclerodermia	<a href="https://esclerodermia.com">https://esclerodermia.com</a>	Full Member
Spain	Asociación Española de Familiares y Enfermos de Wilson	<a href="https://enfermedaddewilson.org/">https://enfermedaddewilson.org/</a>	Full Member
Spain	Asociación Española de Fibrodisplasia Osificante Progresiva	<a href="http://www.aefop-es.org">http://www.aefop-es.org</a>	Full Member
Spain	Asociación Española de Fiebre Mediterranea Familiar	<a href="https://fmf.org.es/">https://fmf.org.es/</a>	Full Member
Spain	Asociación Española de Ictiosis	<a href="http://www.ictiosis.org">http://www.ictiosis.org</a>	Full Member
Spain	Asociación Española de Mastocitosis y Enfermedades Relacionadas	<a href="http://www.mastocitosis.com">http://www.mastocitosis.com</a>	Full Member
Spain	Asociación Española de Pacs1	<a href="http://pacs1.es/">http://pacs1.es/</a>	Associate Member
Spain	Asociación Española de paraparesia espástica familiar Strümpell-Lorrai	<a href="http://www.aepef.org">http://www.aepef.org</a>	Full Member
Spain	Asociación Española de Porfiria	<a href="http://www.porfiria.org">http://www.porfiria.org</a>	Full Member
Spain	Asociación Española de Raquitismos y Osteomalacia Heredados	<a href="https://aeryoh.org/">https://aeryoh.org/</a>	Associate Member
Spain	Asociación Española de Síndrome De Poland	<a href="http://www.aesip.es">http://www.aesip.es</a>	Full Member
Spain	Asociación Española de Síndrome Tatton Brown Rahmna		Full Member
Spain	Asociación Española de Síndromes Compresivos Vasculares	<a href="https://www.aescov.es/">https://www.aescov.es/</a>	Full Member
Spain	Asociación Española de Sjögren	<a href="http://www.aesjogren.org">http://www.aesjogren.org</a>	Full Member
Spain	Asociación Espanola deficit de Lipasa Acida Lisosomal	<a href="http://www.aelald.org">http://www.aelald.org</a>	Full Member
Spain	Asociación Española del síndrome CDG	<a href="http://aescdg.com/">http://aescdg.com/</a>	Associate Member
Spain	Asociación Española del Síndrome de Schaaf-Yang	<a href="https://www.aesys.org/">https://www.aesys.org/</a>	Full Member
Spain	Asociación HHT España	<a href="http://www.asociacionhht.org">http://www.asociacionhht.org</a>	Full Member
Spain	Asociación KIF1A España	<a href="https://kif1a.es/">https://kif1a.es/</a>	Full Member
Spain	Asociación Kleefstra España	<a href="https://www.kleefstra.es/">https://www.kleefstra.es/</a>	Associate Member
Spain	Asociación Madrileña de Pacientes con Síndrome de Gille de la Tourett	<a href="https://www.ampastta.com/">https://www.ampastta.com/</a>	Full Member
Spain	Asociación Nacional Amigos De Arnold Chiari	<a href="http://www.arnoldchiari.es/">http://www.arnoldchiari.es/</a>	Full Member
Spain	Asociación Nacional de Afectados por Síndromes de Ehlers Danlos e Hi	<a href="http://ansedh.org/">http://ansedh.org/</a>	Full Member
Spain	Asociacion Nacional de Dermatomiositis Juvenil	<a href="https://anadeju.org/">https://anadeju.org/</a>	Full Member
Spain	Asociación Nacional de Hipertensión Pulmonar	<a href="https://hipertensionpulmonar.es/">https://hipertensionpulmonar.es/</a>	Full Member
Spain	Asociación Nacional Síndrome de Apert y otras Craneosinostosis Sindri	<a href="http://www.ansapert.org">http://www.ansapert.org</a>	Full Member
Spain	Asociación Retina Murcia	<a href="https://www.retinamurcia.org/">https://www.retinamurcia.org/</a>	Full Member
Spain	Asociación Síndrome de Angelman	<a href="https://angelman-asa.org/">https://angelman-asa.org/</a>	Full Member
Spain	Asociacion síndrome de la persona rígida -stiffperson-sps	<a href="https://asociacionsindromepersonarigi">https://asociacionsindromepersonarigi</a>	Full Member
Spain	Asociación Stop Sanfilippo	<a href="https://www.stopsanfilippo.org/">https://www.stopsanfilippo.org/</a>	Associate Member
Spain	Asociación Xeroderma Pigmentosum	<a href="https://xerodermapigmentosum.es/">https://xerodermapigmentosum.es/</a>	Full Member

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Country/Region	Organisation	Website	Membership
Spain	Associacio Antian		Associate Member
Spain	Associacio Catalana de la Deleccio 22Q	<a href="http://www.22q.cat">http://www.22q.cat</a>	Full Member
Spain	Associació d'Apràxia Ocular i Malalties Associades	<a href="http://apraxiaocular.blogspot.com">http://apraxiaocular.blogspot.com</a>	Associate Member
Spain	Asociación Catalana de Enfermedades Neuromusculares	<a href="http://www.asecatalunya.com">http://www.asecatalunya.com</a>	Full Member
Spain	Atrofia Multisistémica España	<a href="https://msespana.org/">https://msespana.org/</a>	Associate Member
Spain	De Neu - Asociación De Enfermedades De Los Neurotransmisores	<a href="http://www.deneu.org">http://www.deneu.org</a>	Full Member
Spain	Duchenne Parent Project España	<a href="http://www.duchenne-spain.org">http://www.duchenne-spain.org</a>	Full Member
Spain	Enfermedades Raras Mas Visibles	<a href="https://www.masvisibles.com/">https://www.masvisibles.com/</a>	Associate Member
Spain	European Network For Rare And Congenital Anaemias	<a href="http://www.enerca.org">http://www.enerca.org</a>	Associate Member
Spain	FEDER - Federación Española de Enfermedades Raras	<a href="https://www.enfermedades-raras.org">https://www.enfermedades-raras.org</a>	Full Member
Spain	Federació Catalana de Malalties Minoritàries	<a href="https://www.fecamm.org/portal1/m_ir">https://www.fecamm.org/portal1/m_ir</a>	Full Member
Spain	Federacion de Asociaciones de Distrofias Hereditarias de Retina de Esp	<a href="http://www.retinosifarpe.org">http://www.retinosifarpe.org</a>	Full Member
Spain	Federación Española de Enfermedades Neuromusculares	<a href="http://www.asec-esp.org">http://www.asec-esp.org</a>	Full Member
Spain	Federación Española de Familias de Cáncer Infantil	<a href="https://www.cancerinfantil.org">https://www.cancerinfantil.org</a>	Full Member
Spain	Federación Española De Fibrosis Quística	<a href="http://www.fibrosis.org/">http://www.fibrosis.org/</a>	Full Member
Spain	Federación Española De Hemofilia	<a href="http://www.hemofilia.com">http://www.hemofilia.com</a>	Full Member
Spain	Federación Española del Síndrome X Frágil	<a href="http://www.xfragil.org">http://www.xfragil.org</a>	Full Member
Spain	Fundació Síndrome d'Usher	<a href="https://savesightnoweurope.org/">https://savesightnoweurope.org/</a>	Full Member
Spain	Fundación ALPE Acondroplasia	<a href="https://www.fundacionalpe.org">https://www.fundacionalpe.org</a>	Full Member
Spain	Fundación Andrés Marcio, Niños Contra La Laminopatía	<a href="http://www.fundacionandresmarcio.or">http://www.fundacionandresmarcio.or</a>	Full Member
Spain	Fundación contra La Hipertensión Pulmonal	<a href="https://www.fchp.es/">https://www.fchp.es/</a>	Associate Member
Spain	Fundacion Libellas	<a href="https://fundacionlibellas.org">https://fundacionlibellas.org</a>	Associate Member
Spain	Fundación Mari Paz Jiménez Casado	<a href="https://www.fundacionmaripazjimenez">https://www.fundacionmaripazjimenez</a>	Full Member
Spain	Fundación Niemann-Pick de España	<a href="http://www.fnp.es">http://www.fnp.es</a>	Full Member
Spain	Fundacion Noelia, Collagen VI Deficiency Muscular Dystrophy	<a href="https://fundacionnoelia.org/">https://fundacionnoelia.org/</a>	Full Member
Spain	Fundación Síndrome 5P Menos	<a href="http://www.fundacionsindrome5p.org">http://www.fundacionsindrome5p.org</a>	Full Member
Spain	Fundación Síndrome de Dravet - Dravet Syndrome Foundation	<a href="http://www.dravetfoundation.eu">http://www.dravetfoundation.eu</a>	Full Member
Spain	Fundacion Síndrome De West	<a href="http://www.sindromedewest.org">http://www.sindromedewest.org</a>	Full Member
Spain	Fundación Síndrome Wolf Hirschhorn 4P-	<a href="https://www.fundacion4pmenos.com">https://www.fundacion4pmenos.com</a>	Full Member
Spain	Hipertension Pulmonar España Organizacion de Pacientes	<a href="https://hipertension-pulmonar.com/">https://hipertension-pulmonar.com/</a>	Associate Member
Spain	Instituto de Investigación y Desarrollo Social de Enfermedades Poco Fr	<a href="http://www.pocofrecuentes.org">http://www.pocofrecuentes.org</a>	Associate Member
Spain	Menkes International Association	<a href="https://menkesinternational.com/">https://menkesinternational.com/</a>	Full Member



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Spain	MPS-LISOSOMALES España	<a href="https://mpslisosomales.org/">https://mpslisosomales.org/</a>	Full Member
Spain	Pequeños Superheroes	<a href="https://pequenossuperheroes.org/">https://pequenossuperheroes.org/</a>	Associate Member
Spain	SAF España	<a href="https://www.antifosfolipido.es/">https://www.antifosfolipido.es/</a>	Full Member
Spain	SAMS - Asociacion para la lucha contra los Síndromes Arrítmicos Relaci	<a href="https://www.samsasociacion.com/">https://www.samsasociacion.com/</a>	Full Member
Spain	Sense Barreres de Petrer	<a href="https://sensebarreres.es/">https://sensebarreres.es/</a>	Associate Member
Spain	SIMA Asociación de afectados Síndrome de Marfan	<a href="http://www.marfan.es/">http://www.marfan.es/</a>	Full Member
Sweden	Agrenska	<a href="http://www.agrenska.se">http://www.agrenska.se</a>	Full Member
Sweden	Aorta Dissektion Föreningen Skandinavien	<a href="https://aortadissektion.com/en/">https://aortadissektion.com/en/</a>	Full Member
Sweden	DysNet	<a href="https://www.dysnet.org/">https://www.dysnet.org/</a>	Full Member
Sweden	European Cavernoma Alliance	<a href="https://sites.google.com/cavernostangi">https://sites.google.com/cavernostangi</a>	Associate Member
Sweden	Neuroförbundet / Swedish Association Of Persons With Neurological I	<a href="http://neuroforbundet.se">http://neuroforbundet.se</a>	Associate Member
Sweden	Prader Willi Syndrome Association in Sweden	<a href="https://prader-willi.se/">https://prader-willi.se/</a>	Full Member
Sweden	Primär Immunbrist Organisationen	<a href="http://www.pio.nu">http://www.pio.nu</a>	Full Member
Sweden	Rare Diseases Sweden (Riksförbundet Sällsynta Diagnoser)	<a href="https://www.sallsyntadiagnoser.se/">https://www.sallsyntadiagnoser.se/</a>	Full Member
Sweden	Svenska Marfanföreningen - Swedish Marfan Assciation	<a href="http://www.marfanforeningen.se/">http://www.marfanforeningen.se/</a>	Full Member
Sweden	Svenska Ödemförbundet (Swedish Association of Chronic Oedema)	<a href="https://www.svenskaodemforbundet.se">https://www.svenskaodemforbundet.se</a>	Associate Member
Sweden	Swedish Cystic Fibrosis Association	<a href="https://www.rfcf.se/">https://www.rfcf.se/</a>	Full Member
Sweden	Swedish EDS Association (EDS Riksförbund)	<a href="https://ehlers-danlos.se/">https://ehlers-danlos.se/</a>	Full Member
Sweden	Swedish MPS Society (Svenska MPS Föreningen)	<a href="https://mpsforeningen.se/">https://mpsforeningen.se/</a>	Full Member
Sweden	Thyroid Federation International	<a href="https://thyroid-fed.org/">https://thyroid-fed.org/</a>	Associate Member
Sweden	Wilhelm Foundation	<a href="https://wilhelmfoundation.org/">https://wilhelmfoundation.org/</a>	Full Member
Switzerland	AGO Alliance	<a href="https://argonauts.ngo">https://argonauts.ngo</a>	Associate Member
Switzerland	Association Enfance et Maladies Orphelines	<a href="http://www.aemo.ch">http://www.aemo.ch</a>	Associate Member
Switzerland	Association OrphanHealthcare, for Families with Rare Diseases	<a href="http://www.orphanhealthcare.org/">http://www.orphanhealthcare.org/</a>	Associate Member
Switzerland	Blackswan Foundation	<a href="http://www.blackswanfoundation.ch">http://www.blackswanfoundation.ch</a>	Associate Member
Switzerland	CML Advocates Network	<a href="http://www.cmladvocates.net">http://www.cmladvocates.net</a>	Associate Member
Switzerland	Esperare	<a href="http://www.esperare.org">http://www.esperare.org</a>	Associate Member
Switzerland	FMF & AID Global Association	<a href="http://www.fmfandaaid.org">http://www.fmfandaaid.org</a>	Associate Member
Switzerland	Fondation Sanfilippo Suisse	<a href="https://www.fondation-sanfilippo.ch/">https://www.fondation-sanfilippo.ch/</a>	Associate Member
Switzerland	Fraxas - Association X Fragile Suisse	<a href="http://www.fraxas.ch">http://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	<a href="http://www.hhtswiss.org">http://www.hhtswiss.org</a>	Associate Member



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Switzerland	MaRaVal – maladies rares valais – seltene krankheiten wallis.	<a href="https://www.maraval.ch/">https://www.maraval.ch/</a>	Full Member
Switzerland	Marfan Foundation Switzerland (Marfan Stiftung Schweiz)	<a href="http://www.marfan.ch">http://www.marfan.ch</a>	Full Member
Switzerland	Prader Willi Syndrom Vereinigung Schweiz	<a href="https://www.prader-willi.ch/">https://www.prader-willi.ch/</a>	Full Member
Switzerland	Proraris	<a href="https://www.proraris.ch/">https://www.proraris.ch/</a>	Full Member
Switzerland	Save sight now Europe	<a href="https://savesightnoweurope.org/">https://savesightnoweurope.org/</a>	Associate Member
Switzerland	Schweizerische Gesellschaft Für Porphyrrie	<a href="http://www.porphyrria.ch">http://www.porphyrria.ch</a>	Full Member
Switzerland	Sjögren Europe	<a href="http://sjogreneurope.org/">http://sjogreneurope.org/</a>	Associate Member
Switzerland	SLC6A1 Switzerland		Associate Member
Switzerland	SMA Schweiz	<a href="http://www.sma-schweiz.ch">http://www.sma-schweiz.ch</a>	Associate Member
Switzerland	Swiss FH/Schweizerische Gesellschaft für familiäre Formen der Hyperc	<a href="http://www.sgfh.ch">http://www.sgfh.ch</a>	Associate Member
Switzerland	Verband Angiodysplasie Schweiz	<a href="https://angiodysplasie.ch">https://angiodysplasie.ch</a>	Associate Member
Taiwan, Province of China	Taiwan Foundation for Rare Disorders	<a href="https://www.tfrd.org.tw/tfrd/">https://www.tfrd.org.tw/tfrd/</a>	Associate Member
Turkey	DMD Aileleri Derneği (DMD Families Association)	<a href="https://www.dmdaileleri.org/">https://www.dmdaileleri.org/</a>	Full Member
Turkey	Duchenne Kas Hastalığı Ile Mucadele Dernegi	<a href="http://dmdturkiye.org/">http://dmdturkiye.org/</a>	Full Member
Turkey	Kifder	<a href="http://www.kifder.org.tr">http://www.kifder.org.tr</a>	Associate Member
Turkey	Mukopolisakkaridoz ve Benzeri Lizozomal Depo Hastalıkları Dernegi /	<a href="http://www.mpsturk.org">http://www.mpsturk.org</a>	Associate Member
Turkey	Pulmoner Hipertansiyon ve Skleroderma Hasta Derneği / PHA Turkey	<a href="http://www.pahssc.org.tr">http://www.pahssc.org.tr</a>	Full Member
Turkey	Sistinozis Hastaları Dernegi / Cistinosis Patients Association	<a href="https://www.sistinder.org/">https://www.sistinder.org/</a>	Associate Member
Turkey	Türkiye SMA Foundation	<a href="https://www.sma.org.tr/">https://www.sma.org.tr/</a>	Full Member
Turkey	Yuzumle Mutluyum Dernegi/Happy Faces	<a href="http://www.yuzumlemutluyum.org.tr">http://www.yuzumlemutluyum.org.tr</a>	Associate Member
Ukraine	Charitable Foundation "Sister Dalila	<a href="https://poryatunok.info/">https://poryatunok.info/</a>	Full Member
Ukraine	Charitable Foundation Zaporuka	<a href="https://zaporuka.org.ua/">https://zaporuka.org.ua/</a>	Associate Member
Ukraine	Children with Spinal Muscular Atrophy, Charitable Foundation	<a href="https://csma.org.ua/">https://csma.org.ua/</a>	Full Member
Ukraine	Patients of Ukraine	<a href="https://patients.org.ua/en/">https://patients.org.ua/en/</a>	Associate Member
Ukraine	Pulmonary Hypertension Ukrainian Rare Disease Association	<a href="https://www.facebook.com/profile.php">https://www.facebook.com/profile.php</a>	Full Member
Ukraine	Rare Diseases of Ukraine	<a href="https://www.facebook.com/orphandis">https://www.facebook.com/orphandis</a>	Full Member
Ukraine	Ukrainian Association Crystal People		Associate Member
Ukraine	Ukrainian Association of Help for Patients with CF	<a href="http://facebook.com/cysticfibrosisua">http://facebook.com/cysticfibrosisua</a>	Full Member
Ukraine	Ukrainian Parent Project "Mio-Life"	<a href="http://miolife.org">http://miolife.org</a>	Associate Member
United Kingdom of Great B	Acrodysostosis Support and Research	<a href="http://www.acrodysostosis.com">http://www.acrodysostosis.com</a>	Associate Member
United Kingdom of Great B	Action Duchenne	<a href="http://www.actionduchenne.org">http://www.actionduchenne.org</a>	Full Member
United Kingdom of Great B	Advocacy For Neuroacanthocytosis Patients	<a href="http://www.naadvocacy.org">http://www.naadvocacy.org</a>	Associate Member

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United Kingdom of Great B	AKU Society	<a href="https://www.akusociety.org">https://www.akusociety.org</a>	Full Member
United Kingdom of Great B	Alex The Leukodystrophy Charity	<a href="https://www.alextlc.org/">https://www.alextlc.org/</a>	Associate Member
United Kingdom of Great B	Alport UK	<a href="http://www.alportuk.org/">http://www.alportuk.org/</a>	Full Member
United Kingdom of Great B	Alstrom Syndrome Europe	<a href="https://www.alstrom.org.uk/as-europe">https://www.alstrom.org.uk/as-europe</a>	Associate Member
United Kingdom of Great B	Alstrom Syndrome UK	<a href="http://www.alstrom.org.uk">http://www.alstrom.org.uk</a>	Full Member
United Kingdom of Great B	Amyloidosis UK	<a href="https://ttramylodosis.uk/">https://ttramylodosis.uk/</a>	Associate Member
United Kingdom of Great B	Annabelle's Challenge	<a href="http://www.annabelleschallenge.org">http://www.annabelleschallenge.org</a>	Full Member
United Kingdom of Great B	Arthur's Quest / SLC6A1 Connect UK	<a href="https://arthursquest.org/">https://arthursquest.org/</a>	Full Member
United Kingdom of Great B	Association for Glycogen Storage Disease	<a href="http://www.agsd.org.uk">http://www.agsd.org.uk</a>	Full Member
United Kingdom of Great B	Association for Multiple Endocrine Neoplasia Disorders	<a href="http://www.amend.org.uk">http://www.amend.org.uk</a>	Full Member
United Kingdom of Great B	Ataxia UK	<a href="https://www.ataxia.org.uk/">https://www.ataxia.org.uk/</a>	Full Member
United Kingdom of Great B	Batten Disease Family Association	<a href="http://www.bdfa-uk.org.uk/">http://www.bdfa-uk.org.uk/</a>	Full Member
United Kingdom of Great B	Beacon for Rare Diseases	<a href="https://www.rarebeacon.org/">https://www.rarebeacon.org/</a>	Associate Member
United Kingdom of Great B	Behcet's UK	<a href="https://behcetsuk.org/">https://behcetsuk.org/</a>	Full Member
United Kingdom of Great B	Brittle Bone Society	<a href="http://www.brittlebone.org">http://www.brittlebone.org</a>	Associate Member
United Kingdom of Great B	Cambridge Rare Disease Network	<a href="https://www.camraredisease.org/">https://www.camraredisease.org/</a>	Associate Member
United Kingdom of Great B	Cancer 52	<a href="http://www.cancer52.org.uk">http://www.cancer52.org.uk</a>	Associate Member
United Kingdom of Great B	CASK Research Foundation	<a href="https://caskresearch.org/">https://caskresearch.org/</a>	Full Member
United Kingdom of Great B	Cavernoma Alliance UK	<a href="http://www.cavernoma.org.uk">http://www.cavernoma.org.uk</a>	Full Member
United Kingdom of Great B	CDG UK	<a href="https://cdg-uk.org/">https://cdg-uk.org/</a>	Full Member
United Kingdom of Great B	CDH International	<a href="https://cdhi.org/">https://cdhi.org/</a>	Associate Member
United Kingdom of Great B	CDH UK	<a href="http://www.cd huk.org.uk/">http://www.cd huk.org.uk/</a>	Full Member
United Kingdom of Great B	CHAMP1 UK	<a href="https://champ1.uk/">https://champ1.uk/</a>	Associate Member
United Kingdom of Great B	Child Growth Foundation	<a href="http://www.childgrowthfoundation.org">http://www.childgrowthfoundation.org</a>	Full Member
United Kingdom of Great B	Child Lung Foundation	<a href="http://www.childlungfoundation.org">http://www.childlungfoundation.org</a>	Associate Member
United Kingdom of Great B	Childhood Tumor Trust	<a href="https://www.childhoodtumourtrust.org">https://www.childhoodtumourtrust.org</a>	Full Member
United Kingdom of Great B	Children's Liver Disease Foundation	<a href="http://www.childliverdisease.org">http://www.childliverdisease.org</a>	Associate Member
United Kingdom of Great B	Ciliopathy Alliance	<a href="http://www.ciliopathyalliance.org">http://www.ciliopathyalliance.org</a>	Full Member
United Kingdom of Great B	Contact A Family	<a href="http://www.cafamily.org.uk">http://www.cafamily.org.uk</a>	Full Member
United Kingdom of Great B	CPA Research Foundation	<a href="https://www.cparfoundation.org/">https://www.cparfoundation.org/</a>	Full Member
United Kingdom of Great B	Cure CLCN4	<a href="https://cureclcn4.org/">https://cureclcn4.org/</a>	Associate Member
United Kingdom of Great B	Cure Myotonic Dystrophy UK Charity	<a href="https://www.congenitalmyotonicdystro">https://www.congenitalmyotonicdystro</a>	Full Member

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United Kingdom of Great B	Cystinosis Foundation UK	<a href="http://www.cystinosis.org.uk">http://www.cystinosis.org.uk</a>	Full Member
United Kingdom of Great B	Dancing Eye Syndrome Support Trust	<a href="http://www.dancingeyes.org.uk">http://www.dancingeyes.org.uk</a>	Full Member
United Kingdom of Great B	EOS Network Eosinophilic Diseases Charity	<a href="https://www.eosnetwork.org/">https://www.eosnetwork.org/</a>	Associate Member
United Kingdom of Great B	European Lung Foundation	<a href="http://www.european-lung-foundation">http://www.european-lung-foundation</a>	Associate Member
United Kingdom of Great B	European Tuberous Sclerosis Complex Association	<a href="http://www.e-tsc.eu">http://www.e-tsc.eu</a>	Full Member
United Kingdom of Great B	Eyes on the Future	<a href="https://eyesonthefuture.org.uk/">https://eyesonthefuture.org.uk/</a>	Associate Member
United Kingdom of Great B	Fetal Anti Convulsant Syndrome Association		Associate Member
United Kingdom of Great B	FOP Friends	<a href="https://www.fopfriends.com">https://www.fopfriends.com</a>	Full Member
United Kingdom of Great B	Gauchers Association UK	<a href="http://www.gaucher.org.uk">http://www.gaucher.org.uk</a>	Full Member
United Kingdom of Great B	Genetic Alliance UK	<a href="https://geneticalliance.org.uk/">https://geneticalliance.org.uk/</a>	Full Member
United Kingdom of Great B	Glut1 Deficiency UK	<a href="http://www.glut1deficiency.org.uk">http://www.glut1deficiency.org.uk</a>	Associate Member
United Kingdom of Great B	HBA Support	<a href="https://www.hbasupport.org/">https://www.hbasupport.org/</a>	Associate Member
United Kingdom of Great B	Hope for Histi	<a href="https://www.hopeforhisti.org/">https://www.hopeforhisti.org/</a>	Associate Member
United Kingdom of Great B	Hope for Hypothalamic Hamartomas UK	<a href="http://www.hopeforhh.org">http://www.hopeforhh.org</a>	Full Member
United Kingdom of Great B	Huntington's Disease Youth Organisation	<a href="https://en.hdyo.org/">https://en.hdyo.org/</a>	Full Member
United Kingdom of Great B	International Brain Tumour Alliance	<a href="http://www.theibta.org">http://www.theibta.org</a>	Associate Member
United Kingdom of Great B	International Gaucher Alliance	<a href="https://gaucheralliance.org/">https://gaucheralliance.org/</a>	Full Member
United Kingdom of Great B	International Niemann-Pick Disease Alliance	<a href="https://www.inpda.org">https://www.inpda.org</a>	Full Member
United Kingdom of Great B	International Patient Organization for Primary Immunodeficiencies	<a href="https://ipopi.org/">https://ipopi.org/</a>	Full Member
United Kingdom of Great B	International Prader-Willi Syndrome Organisation	<a href="http://www.ipwso.org">http://www.ipwso.org</a>	Full Member
United Kingdom of Great B	ITP Support Association	<a href="https://www.itpsupport.org.uk">https://www.itpsupport.org.uk</a>	Full Member
United Kingdom of Great B	Joining Jack	<a href="http://www.joiningjack.org">http://www.joiningjack.org</a>	Full Member
United Kingdom of Great B	Krabbe UK	<a href="https://www.krabbeuk.org/">https://www.krabbeuk.org/</a>	Full Member
United Kingdom of Great B	Leber's Hereditary Optic Neuropathy Society	<a href="http://www.lhonsociety.org">http://www.lhonsociety.org</a>	Full Member
United Kingdom of Great B	LGD Alliance Europe	<a href="http://www.lgda.eu">http://www.lgda.eu</a>	Full Member
United Kingdom of Great B	Max Appeal	<a href="http://www.maxappeal.org.uk">http://www.maxappeal.org.uk</a>	Full Member
United Kingdom of Great B	Mebo Research	<a href="http://www.meboreserach.org">http://www.meboreserach.org</a>	Associate Member
United Kingdom of Great B	Metabolic Support UK	<a href="https://metabolicsupportuk.org/">https://metabolicsupportuk.org/</a>	Full Member
United Kingdom of Great B	MPS Society	<a href="https://www.mppsociety.org.uk/">https://www.mppsociety.org.uk/</a>	Full Member
United Kingdom of Great B	MVA Society	<a href="https://mvasociety.org/">https://mvasociety.org/</a>	Associate Member
United Kingdom of Great B	Myaware	<a href="https://www.myaware.org/">https://www.myaware.org/</a>	Full Member
United Kingdom of Great B	Myotubular Trust	<a href="http://www.myotubulartrust.org">http://www.myotubulartrust.org</a>	Full Member

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Country/Region	Organisation	Website	Membership
United Kingdom of Great B	Niemann-Pick UK	<a href="https://www.npuk.org/">https://www.npuk.org/</a>	Full Member
United Kingdom of Great B	Northern Ireland Rare Disease Partnership	<a href="https://dev.nirdp.org.uk/">https://dev.nirdp.org.uk/</a>	Full Member
United Kingdom of Great B	Opie Jones Foundation	<a href="https://www.opiejonesfoundation.com">https://www.opiejonesfoundation.com</a>	Associate Member
United Kingdom of Great B	Pathfinders Neuromuscular Alliance	<a href="https://www.pathfindersalliance.org.uk">https://www.pathfindersalliance.org.uk</a>	Full Member
United Kingdom of Great B	PCD Research	<a href="https://pcdresearch.org/">https://pcdresearch.org/</a>	Associate Member
United Kingdom of Great B	PIP-UK Poland Syndrome Support	<a href="https://pip-uk.org/">https://pip-uk.org/</a>	Full Member
United Kingdom of Great B	Pitt Hopkins UK	<a href="http://pitthopkins.org.uk/">http://pitthopkins.org.uk/</a>	Full Member
United Kingdom of Great B	Polycystic Kidney Disease Charity	<a href="https://pkdcharity.org.uk">https://pkdcharity.org.uk</a>	Full Member
United Kingdom of Great B	Pompe Support Network	<a href="https://pompe.uk/">https://pompe.uk/</a>	Full Member
United Kingdom of Great B	PSC Support	<a href="https://pscsupport.org.uk/">https://pscsupport.org.uk/</a>	Full Member
United Kingdom of Great B	Pseudomyxoma Survivor	<a href="http://www.pseudomyxomasurvivor.cc">http://www.pseudomyxomasurvivor.cc</a>	Associate Member
United Kingdom of Great B	Pten Research Foundation	<a href="https://www.ptenresearch.org/">https://www.ptenresearch.org/</a>	Associate Member
United Kingdom of Great B	Rare Autoinflammatory Conditions Community- UK	<a href="http://www.raccuk.com">http://www.raccuk.com</a>	Associate Member
United Kingdom of Great B	Rare Disease Male Mental Health Support Group		Associate Member
United Kingdom of Great B	Rare Disease UK	<a href="https://geneticalliance.org.uk/">https://geneticalliance.org.uk/</a>	Associate Member
United Kingdom of Great B	Reverse Rett UK	<a href="http://www.reverserett.org.uk/">http://www.reverserett.org.uk/</a>	Full Member
United Kingdom of Great B	Ring 20 Research and Support UK CIO	<a href="http://ring20researchsupport.co.uk/">http://ring20researchsupport.co.uk/</a>	Associate Member
United Kingdom of Great B	Salivary Gland Cancer UK	<a href="https://www.salivaryglandcancer.uk/">https://www.salivaryglandcancer.uk/</a>	Associate Member
United Kingdom of Great B	Schinz-Giedion Syndrome Foundation	<a href="https://sgsfoundation.org/">https://sgsfoundation.org/</a>	Associate Member
United Kingdom of Great B	Smile with Shiv	<a href="http://smilewithshiv.org/">http://smilewithshiv.org/</a>	Associate Member
United Kingdom of Great B	Stargardt's Connected	<a href="https://stargardtsconnected.org.uk/">https://stargardtsconnected.org.uk/</a>	Full Member
United Kingdom of Great B	Stiff Person Support Group	<a href="https://lizblows.wixsite.com/spsuk">https://lizblows.wixsite.com/spsuk</a>	Full Member
United Kingdom of Great B	Sturge-Weber UK	<a href="http://www.sturgetweber.org.uk">http://www.sturgetweber.org.uk</a>	Full Member
United Kingdom of Great B	The AADC Research Trust Children's Charity	<a href="https://www.aadcresearch.org/">https://www.aadcresearch.org/</a>	Full Member
United Kingdom of Great B	The Aarskog Foundation	<a href="http://www.aarskogsyndromeofoundation">http://www.aarskogsyndromeofoundation</a>	Associate Member
United Kingdom of Great B	The Children's Hyperinsulinism Charity	<a href="http://www.hyperinsulinism.co.uk">http://www.hyperinsulinism.co.uk</a>	Full Member
United Kingdom of Great B	The Chromosome 18 Registry and Research Society (Europe)	<a href="https://chromosome18eur.org/">https://chromosome18eur.org/</a>	Associate Member
United Kingdom of Great B	The Cure & Action For Tay-Sachs (Cats) Foundation	<a href="http://www.cats-foundation.org">http://www.cats-foundation.org</a>	Full Member
United Kingdom of Great B	The ED Society	<a href="https://edsociety.co.uk/">https://edsociety.co.uk/</a>	Full Member
United Kingdom of Great B	The EHE Rare Cancer Charity	<a href="https://www.ehercc.org.uk/">https://www.ehercc.org.uk/</a>	Full Member
United Kingdom of Great B	The Ehlers-Danlos Society	<a href="https://www.ehlers-danlos.com/">https://www.ehlers-danlos.com/</a>	Full Member
United Kingdom of Great B	The Fragile X Society	<a href="http://www.fragilex.org.uk/">http://www.fragilex.org.uk/</a>	Full Member

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United Kingdom of Great Britain	The Maddi Foundation	<a href="https://themaddifoundation.com/">https://themaddifoundation.com/</a>	Associate Member
United Kingdom of Great Britain	The PBC Foundation (UK) Ltd	<a href="https://www.pbcfoundation.org.uk/">https://www.pbcfoundation.org.uk/</a>	Associate Member
United Kingdom of Great Britain	Timothy Syndrome Alliance	<a href="https://timothysyndrome.org.uk/">https://timothysyndrome.org.uk/</a>	Full Member
United Kingdom of Great Britain	TTPNetwork	<a href="https://www.ttpnetwork.org.uk/">https://www.ttpnetwork.org.uk/</a>	Associate Member
United Kingdom of Great Britain	Tuberous Sclerosis Association	<a href="https://tuberous-sclerosis.org/">https://tuberous-sclerosis.org/</a>	Full Member
United Kingdom of Great Britain	UK Mastocytosis Support Group	<a href="https://ukmasto.org/">https://ukmasto.org/</a>	Full Member
United Kingdom of Great Britain	Unique - Rare Chromosome Disorder Support Group	<a href="https://rarechromo.org/">https://rarechromo.org/</a>	Full Member
United Kingdom of Great Britain	United Kingdom Thalassaemia Society	<a href="http://www.ukts.org">http://www.ukts.org</a>	Full Member
United Kingdom of Great Britain	Vasculitis UK (The Vasculitis Trust)	<a href="http://www.vasculitis.org.uk">http://www.vasculitis.org.uk</a>	Full Member
United Kingdom of Great Britain	VHL UK/Ireland	<a href="https://vhl-uk-ireland.org">https://vhl-uk-ireland.org</a>	Full Member
United States of America	Alagille Syndrome Alliance	<a href="http://www.alagille.org">http://www.alagille.org</a>	Associate Member
United States of America	Alstrom Syndrome International	<a href="https://www.alstrom.org/">https://www.alstrom.org/</a>	Associate Member
United States of America	APS Foundation of America, Inc	<a href="http://www.apsfa.org">http://www.apsfa.org</a>	Associate Member
United States of America	Association for Creatine Deficiencies	<a href="https://creatineinfo.org/">https://creatineinfo.org/</a>	Associate Member
United States of America	BCM Families Foundation	<a href="http://www.blueconemonochromacy.org">http://www.blueconemonochromacy.org</a>	Associate Member
United States of America	CACNA1A Foundation	<a href="https://www.cacna1a.org/">https://www.cacna1a.org/</a>	Associate Member
United States of America	CLOVES Syndrome Community	<a href="https://clovesysndrome.org/">https://clovesysndrome.org/</a>	Associate Member
United States of America	Cure LBSL	<a href="https://www.curelbsl.org">https://www.curelbsl.org</a>	Associate Member
United States of America	Cure Mucopolysaccharidosis	<a href="https://www.curemucopolysaccharidosis.org/">https://www.curemucopolysaccharidosis.org/</a>	Associate Member
United States of America	Cure PSP	<a href="http://www.curepsp.org">http://www.curepsp.org</a>	Associate Member
United States of America	Defeat MSA Alliance Defeat Multiple System Atrophy Alliance.	<a href="https://defeatmsa.org">https://defeatmsa.org</a>	Associate Member
United States of America	FMD Chat	<a href="http://fmdchat.blogspot.fr/">http://fmdchat.blogspot.fr/</a>	Associate Member
United States of America	GACI Global	<a href="https://gaciglobal.org">https://gaciglobal.org</a>	Associate Member
United States of America	GBS/CIDP Foundation International	<a href="https://www.gbs-cidp.org/">https://www.gbs-cidp.org/</a>	Associate Member
United States of America	Hypertrophic Olivary Degeneration Association	<a href="https://HODAssoc.org">https://HODAssoc.org</a>	Associate Member
United States of America	International Foxg1 Foundation	<a href="http://foxg1.org">http://foxg1.org</a>	Associate Member
United States of America	International Pemphigus & Pemphigoid Foundation	<a href="http://www.pemphigus.org">http://www.pemphigus.org</a>	Associate Member
United States of America	International Sacral Agenesis/Caudal Regression Association	<a href="http://isacra.org/">http://isacra.org/</a>	Associate Member
United States of America	International WAGR Syndrome Association	<a href="http://wagr.org/">http://wagr.org/</a>	Associate Member
United States of America	International Waldenstrom's Macroglobulinemia Foundation	<a href="https://iwmf.com/">https://iwmf.com/</a>	Associate Member
United States of America	Malan Syndrome Foundation	<a href="https://www.malansyndrome.org/">https://www.malansyndrome.org/</a>	Associate Member
United States of America	MCT8-AHDS Foundation Inc.	<a href="http://www.mct8.info">http://www.mct8.info</a>	Associate Member

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United States of America	MitoAction	<a href="https://www.mitoaction.org/">https://www.mitoaction.org/</a>	Associate Member
United States of America	Myhre Syndrome Foundation	<a href="https://www.myhresyndrome.org/">https://www.myhresyndrome.org/</a>	Associate Member
United States of America	Neuromuscular Disease Foundation	<a href="https://curegnem.org/">https://curegnem.org/</a>	Associate Member
United States of America	Nord National Organization for Rare Disorders	<a href="https://rarediseases.org/">https://rarediseases.org/</a>	Associate Member
United States of America	NTM Info & Research	<a href="https://ntminfo.org/">https://ntminfo.org/</a>	Associate Member
United States of America	Project 8p Foundation	<a href="https://project8p.org/">https://project8p.org/</a>	Associate Member
United States of America	PTEN Hamartoma Tumor Syndrome Foundation	<a href="http://www.ptenfoundation.org">http://www.ptenfoundation.org</a>	Associate Member
United States of America	Pura Syndrome Foundation	<a href="https://purasyndrome.org/">https://purasyndrome.org/</a>	Associate Member
United States of America	Remember The Girls	<a href="https://rememberthegirls.org/">https://rememberthegirls.org/</a>	Associate Member
United States of America	Sisters' Hope Foundation	<a href="https://sistershopefoundation.com/">https://sistershopefoundation.com/</a>	Associate Member
United States of America	STXBP1 Foundation	<a href="https://www.stxbp1disorders.org/">https://www.stxbp1disorders.org/</a>	Associate Member
United States of America	Superficial Siderosis Research Alliance	<a href="https://ssra.livingwithss.com/">https://ssra.livingwithss.com/</a>	Associate Member
United States of America	Team Titin	<a href="https://titinmyopathy.com/">https://titinmyopathy.com/</a>	Associate Member
United States of America	The Cushing Support & Research Foundation	<a href="https://csrf.net/">https://csrf.net/</a>	Associate Member
United States of America	The Cute Syndrome Foundation	<a href="https://www.thecutesyndrome.com/">https://www.thecutesyndrome.com/</a>	Associate Member
United States of America	The Oxalosis & Hyperoxaluria Foundation	<a href="https://ohf.org/">https://ohf.org/</a>	Associate Member
United States of America	The Snyder-Robinson Foundation	<a href="https://snyder-robinson.org/">https://snyder-robinson.org/</a>	Associate Member
United States of America	Usher Syndrome Coalition	<a href="http://www.usher-syndrome.org">http://www.usher-syndrome.org</a>	Associate Member
Uruguay	Asociacion Acondroplasia Uruguay	<a href="https://www.facebook.com/acondroplasiauruguay">https://www.facebook.com/acondroplasiauruguay</a>	Associate Member
Uruguay	Fundacion Uruguaya para la Investigacion de las Enfermedades Raras	<a href="http://www.fupier.org/">http://www.fupier.org/</a>	Associate Member
Venezuela, Bolivarian Republic of	Fundación Fura	<a href="https://fundacion-fura.mozello.com/">https://fundacion-fura.mozello.com/</a>	Associate Member
Zimbabwe	Child & Youth Care, Zimbabwe	<a href="http://www.cyc.org.zw/">http://www.cyc.org.zw/</a>	Associate Member

