AboutFace USA (For people with facial differences) [http://www.aboutfaceusa.org]
AboutFace International [http://www.aboutfaceinternational.org; http://aboutface.ca/]
Abetalipoproteinemia (International) [http://www.abetalipoproteinemia.org/]
Accord Alliance (Disorders of Sexual Development) [http://www.accordalliance.org/]
Achalasia Support Groups [http://achalasia.us/support_groups.html]
Acid Malate Deficiency Association [http://www.amda-pompe.org/]
Acoustic Neuroma Association [http://anausa.org/]
Addison’s Disease Self Help Group UK [http://www.addisons.org.uk/]
Adinoid Cystic Carcinoma Organization International [http://www.accoi.org/]
Adinoid Cystic Carcinoma Research Foundation [http://www.accrf.org/]
Advocacy for Neuroacanthocytosis Patients [http://www.naadvocacy.org/]
AIS-DSD Support Group USA (Disorders of Sex Development) [http://www.aisdsd.org]
Ais (Androgen Insensitivity Syndrome) Support Group [http://www.aissg.org] (UK based)
AKU (Alkaptonuria) Society [http://www.alkaptonuria.info/]
Alagille Syndrome Alliance [http://www.alagille.org/]
ALS Association (Amyotrophic Lateral Sclerosis) [http://www.alsa.org]
Alopecia Support Group (ASG) [http://www.alopeciasupport.org/]
Alpha-1 Association (Alpha-1 Antitrypsin Deficiency) [http://www.alpha1.org/]
Alpha-1 Canada [http://www.alpha1canada.ca/]
Alpha-1 Foundation [http://www.alpha1foundation.org/]
Alport Syndrome Foundation [http://www.alportsyndrome.org]
Alstrom Syndrome International [http://www.alstrom.org/]
Alternating Hemiplegia of Childhood Foundation [http://ahckids.org/]
Alveolar Capillary Dysplasia Association [http://www.acdassociation.com]
ALS Association (Greater New York Chapter) [http://www.als-ny.org]
Alzheimer’s Association [http://www.alz.org/]
Alzheimer’s Foundation of America [http://www.alzfdn.org/]
Alzheimer’s Association NYC Chapter (Binswanger Disease) [http://www.alznyc.org/relateddisorders/binswanger.asp]
AMEND-Association for Multiple Endocrine Neoplasia Disorders [http://www.amend.org.uk]
American Association for Klinefelter Syndrome Information and Support [http://www.aaksis.org/]
American Association for Pediatric Ophthalmology and Strabismus [http://www.aapos.org/]
American Association of Kidney Patients [http://www.aakp.org/outreach/list]
American Association of the Deaf-Blind (Usher Syndrome) [http://www.aadbo/resources/db_organizations/texas.html]
American Association on Intellectual and Developmental Disabilities [http://www.aamr.org/]
American Autoimmune Related Diseases Association, Inc. [http://www.aarda.org]
American Behcet’s Disease Association [http://www.behcets.org]
American Brain Tumor Association [http://www.abta.org]
American Cancer Society [http://www.cancer.org]
American Childhood Cancer Organization [http://www.acca.org]
American Diabetes Association [http://www.diabetes.org/]
American Epilepsy Society [http://www.aesnet.org]
American Hair Loss Association [http://www.americanhairloss.org]
American Health Assistance Foundation [http://www.ahaf.org/]
American Hearing Research Foundation [http://www.american-hearing.org]
American Heart Association [http://www.heart.org]
American Institute for Cancer Research  http://www.aicr.org
American Kidney Fund, Inc  http://www.kidneyfind.org/
American Lung Association  http://www.lung.org
American Lung Association (Primary Ciliary Dyskinesia, Kartagener’s Syndrome)  http://www.lung.org/lung-disease/primary-ciliary-dyskinesia/
American Macular Degeneration Foundation  http://www.macular.org
American Parkinson Disease Association  http://www.apdaparkinson.org/
American Partnership for Eosinophilic Disorders  http://www.apfed.org
American Porphyria Foundation  http://www.porphyriafoundation.com
American Pregnancy Association  http://www.americanpregnancy.org/
American Self Help Group Clearinghouse  http://www.selfhelpgroups.org/
American Sickle Cell Anemia Association  http://www.ascaa.org
American Stroke Association (Congenital Heart Defects)  http://www.strokeassociation.org
American Syringomyelia and Chiari Alliance Project  http://www.asap.org/
American Thyroid Association  http://www.thyroid.org
American TOS (Thoracic Outlet Syndrome) Association  http://www.atosa.org
American Urological Association Foundation  http://www.urologyhealth.org/
American Uveitis Society  http://www.uveitissociety.org
American Vitiligo Research Foundation  http://www.avrf.org/
AmeriFace (craniofacial defects, anomalies)  http://www.ameriface.org/
Amputee Coalition  http://www.amputee-coalition.org/
Amputee Coalition of America  http://www.mendinglimbs.org
Amyloidosis Australia (Also serves NZ)  http://www.amyloidosis.com.au/
Amyloidosis Foundation  http://www.amyloidosis.org/
Amyotrophic Lateral Sclerosis Association  http://www.alsa.org
Amyotrophic Lateral Sclerosis Society of Canada  http://www.als.ca/
Androgen Insensitivity Syndrome Support Group  http://www.aissg.org/
Anemia Institute for Research and Education  http://optimizinghealth.org/about_aire.php
Angelman Syndrome Foundation  http://www.angelman.org
Aphasia Hope Foundation  http://www.aphasiahope.org/
Angioma Alliance  http://www.angioma.org
Aniridia Foundation International  http://www.aniridia.net/
APS (Antiphospholipid Antibody Syndrome)  http://www.apsfa.org/
AOSupport (Adams Oliver Syndrome)  http://www.aosupport.org
APBD (Adult Polyglucosan Body Disease Research Foundation)  http://www.apbdrf.org
Aplastic Anemia and MDS International Foundation  http://www.aamds.org
APS Foundation of America, Inc.  http://www.apsfa.org/
ARC (People with Intellectual and Developmental Disabilities)  http://www.thearc.org
Arachnoid Cyst Awareness Organization  http://arachnoidcyst1.com/
Arachnoiditis Sufferers Action and Monitoring Society (ACAMS)  http://www.everybody.co.nz/
ARPKD/CHF Alliance (Autosomal Recessive Polycystic Kidney Disease/Congenital Hepatic Fibrosis)  http://www.arpkdchf.org/
Arthritis Foundation  http://www.arthritis.org/
(The)Arthrogryposis Group (UK)  http://www.tagonline.org.uk/
Arthrogryposis Multiplex Congenita Support  
http://health.groups.yahoo.com/group/ArthrogryposisSupport/
Association for Sindrome de Tourette del Peru  http://www.touretteperu.com/
Association for the Bladder Exstrophy Community  http://www.bladderexstrophy.com/
Association for Frontotemporal (Lobar) Degeneration (Dementia)  http://www.theaftd.org/
Association for Glycogen Storage Disease  http://www.agsdus.org/
Association for Glycogen Storage Disease UK  http://www.agsd.org.uk/
Ataxia UK  http://www.ataxia.org.uk/
http://www.mdjunction.com/hemolytic-uremic-syndrome
Australian Leukodystrophy Support Group  http://alsd.au/?n=3
AVM Survivors’ Network (arteriovenous malformations)  http://www.avmsurvivors.org/
Baby’s First Test (Non-Ketotic Hyperglycemia)  http://www.babysfirsttest.org/
Bannyan-Ruvalcaba-Riley Syndrome (Information)  http://www.uihealthcare.org/2column.aspx?id=22904
Barth Syndrome Foundation  http://www.barthsyndrome.org/english/view.asp?x=1
Batten Disease Support and Research Association  http://www.bdsra.org/  (US and Canada with chapters in NZ, Australia, South Africa, South America, and Spain)
BCCNS Life Support Network (Basal Cell Carcinoma Nevus Syndrome)  http://www.bccns.org/
Beckwith-Wiedemann Children’s Foundation  http://www.beckwith-wiedemannsyndrome.org/
Behcet’s Organisation Worldwide  http://www.behcetsuk.org.uk/
Belgian Association for Metabolic Diseases  http://www.boks.be/site/index.php/  (For English, see NORD)
Bell’s Palsy Network  http://www.bellspalsy.net/  (Information source)
Ben’s Friends (Builds Communities for People with Rare Diseases)  http://www.bensfriends.org/
Benign Essential Blepharospasm Research Foundation  http://www.blepharospasm.org/
Benign Paroxysmal Positional Vertigo Support  http://www.experienceproject.com/groups/Have-Benign-Paroxysmal-Positional-Vertigo/89483
Benign Essential Blepharospasm Canadian Research Foundation  http://www.blepharospasm.ca/
Beyond Batten Disease Foundation  http://www.beyondbatten.org/
Biotinidase Deficiency Family Support Group  http://biotinidasedeficiency.20m.com/
Birt-Hogg-Dube Syndrome  http://www.cancer.net/patient/Cancer+Types/Birt-Hogg-Dube+Syndrome/?skid=
Blepharophimosis, Ptosis, Epicanthus, Inversus Family Network  http://www.bpes.org.uk/
Bloom’s Syndrome Foundation (Congenital Telangiectatic Erythema)  http://www.bloomssyndrome.org/
Bruit-Plexus Palsy Foundation  http://www.brachialplexuspalsyfoundation.org/
Brain Foundation  http://www.brain-foundation.org/  (Also Sweden, Canada, Singapore, Australia)
Brain Tumor Foundation for Children, Inc.  http://www.braintumorkids.org/
Breast Cancer Network of Strength  http://www.y-me.org/  (Some information on male and childhood )
Breath of Hope, Inc. (Congenital Diaphragmatic Hernia awareness)  http://breathofhopeinc.com/
Breathtakers (UK)  http://www.breathtakers.org.uk/
BVVL International (Brown-Vialetto-Van Laere Syndrome)  http://www.bvvlinternational.org/
CADASIL -Together We Have Hope (Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy)  http://cadasilfoundation.org/
C&S Patient Education Foundation (Chiari and Syringomalia)  http://www.giveback.org
Canadian Amyloidosis Support Network (CASN)  http://thecasn.org/
Canadian Angelman Syndrome Society  http://www.angelmancanada.org
Canadian Association for Williams Syndrome  http://www.caws-can.org/
Canadian Diabetes Association  http://www.diabetes.ca/
Canadian Directory of Genetic Support Groups  http://www.lhsc.on.ca/Patients_Families_Visitors/Genetic_Support_Directory/
Canadian Hemophilia Society  http://www.hemophilia.ca/
Canadian Immunodeficiencies Patient Organization (CIPO)  http://www.cipo.ca/
Canadian Marfan Association  http://www.marfan.ca/
Canadian Organization for Rare Disorders (CORD)  http://www.raredisorders.ca/
Canadian Pulmonary Fibrosis Foundation  http://www.canadianpulmonaryfibrosis.ca/
Canadian Society for Mucopolysaccharide and Related Disorders  http://www.mpssociety.ca/
Cardiac Arrhythmias Research and Education Foundation, Inc.  http://www.longqt.org/
Cardiomyopathy Association Australia  http://www.cmaa.org.au/
Cares Foundation (Congenital Adrenal Hyperplasia)  http://www.caresfoundation.org/
Canavan Foundation  http://www.canavanfoundation.org/
Canavan Research Foundation  http://www.canavan.org/
Cancer Care  http://www.cancercare.org/
Cancer Coalition of America  http://www.cancercoalition.com/
Cancer Support Community (Search Childhood Colorectal...)  http://www.cancersupportcommunity.org/
Cancer Hope Network  http://www.cancerhopenetwork.org
Cardiac Arrhythmias Research and Education Foundation, Inc.  http://www.longqt.org/
Cardiomyopathy Association Australia  http://www.cmaa.org.au/
Cares Foundation (Congenital Adrenal Hyperplasia)  http://www.caresfoundation.org/
(The)Caregiver Calling (Parkinson’s, Orthostatic Hypotension)  http://thecaregivercalling.com/tag/patient-advocacy/
Caring for the Caregiver  http://caringforthecaregiver.org/
Caring for Carcinoid Foundation  http://www.caringforcarcinoid.org/
Centers for Vulvovaginal Disorders  http://www.cvvd.org/
CdLS Foundation (Cornelia de Lange Syndrome Foundation, Inc.)  http://www.cdlsusa.org/
(The)CDG Family Network (Congenital Disorders of Glycosylation)  http://www.cdg.org/
Cerebral Palsy International Research Foundation  http://www.cpirf.org/
Cerebral Palsy Network (Megalencephany)  http://thecpnetwork.org/megalencephaly.html
CFC International (Cardio-Facio-Cutaneous Syndrome)  http://www.cfcsyndrome.org/
(The)Chagas Disease Foundation  http://www.chagasfound.org/
Charcot-Marie-Tooth Association  http://www.cmtausa.org
Charcot-Marie-Tooth Disease UK  http://www.cmt.org.uk
CHARGE Syndrome Foundation  http://www.chargesyndrome.org/
CHASER (Congenital Heart Abnormalities) Support, Education and Resources  http://www.csun.edu/~hcmth011/chaser/chaser-news.html
CHECKORPHAN (Rare Orphan and Neglected Diseases) http://www.checkorphan.org/
Chelsea’s Hope: Lafora Children Research Fund https://www.chelseashope.org/
Chiari & Syringomyelia Foundation http://www.csinfo.org/
Children Living with Inherited Metabolic Diseases (CLIMB) http://www.CLIMB.org.uk/
Children's Brain Tumor Foundation http://www.cbtf.org/
Children's Brittle Bone Foundation http://www.cbbf.org/
Children’s Cancer & Blood Foundation http://www.childrenscbf.org
Children's Cardiomyopathy Foundation http://www.childrenscardiomyopathy.org/
Children's Craniofacial Association http://www.ccfakekids.com/
Children’s Gaucher Research Fund http://www.childrensgaucher.org/
Children's Neuroblastoma Cancer Foundation http://www.cncfhopec.org/
Children's PKU Network http://www.pkunetwork.org
Children’s Rare Disease Network http://www.crdnetwork.org/footer/diseases/c.php
Children’s Tumor Foundation http://www.ctf.org/
Chordoma Foundation http://www.chordomafoundation.org/
Choroideeremia Research Foundation Canada, Inc. http://www.choroideeremia.ca/
Christopher and Dana Reeve Foundation http://www.christopherreeve.org
Chromosome 18 Registry and Research Society http://www.chromosome18.org/ (worldwide)
Chromosome 22 Support http://www.c22c.org/
Chronic Granulomatous Disease Association, Inc. http://www.cgdassociation.org/
Chronic Granulomatous Disorder Research Trust (CGD) http://www.mobility.embo.org
Chronic Granulomatous Disorder Society http://www.cgdsoociety.org/
Cicatricial Alopecia Research Foundation http://www.carfintl.org
CIDPUSA Foundation (Chronic Inflammatory Demyelinating Polyneuropathy) http://www.cidpusa.org
Churg Strauss Syndrome Association http://www.cssassociation.org/
Cleft Palate Foundation (Operation Smile) http://secure.operationsmile.org
Cleveland Clinic (Patient Support Groups) http://my.clevelandclinic.org/patients-visiters/support-therapy/support-groups.aspx
CLIMB UK (Metabolic Diseases) http://www.climb.org.uk/ (US, Canada, Australia, NZ)
Clot Connect http://dotconnect.org/
CMT United Kingdom (Charcot-Marie Tooth Disease) http://www.cmt.org.uk/
Coalition for Pulmonary Fibrosis http://www.coalitionforpf.org/
Coalition for Usher Syndrome http://www.usher-syndrome.org/
Coats Disease Information for Parents http://www.coatsdisease.org/index.html
Coccygodynia (Experience Project) http://www.experienceproject.com
Coffin-Lowry Syndrome Foundation http://clsf.info/
Collaborative Group of Americas Inherited (Colon Cancer Challenge Foundation) http://www.cgaicc.com/
Colon Cancer Alliance http://www.ccalliance.org/
Congenital Adrenal Hyperplasia Education and Support Network
http://www.congenitaladrenalhyperplasia.org
(See US, Australia, UK)
Congenital Adrenal Hyperplasia Research Education and Support Foundation
http://www.caresfoundation.org/
Congenital Adrenal Hyperplasia Support Group of NZ or CAHNZ Trust http://www.cah.nz/
Congenital Central Hypoventilation Syndrome Family Support Network
http://www.cchsnetwork.org/
Congenital Heart Information Network (CHIN) http://tchin.org/
Congenital Hyperinsulinism International http://www.congenitalhi.org/
Conquer Chiari http://www.conquerchiari.org/index.html
Contact a Family http://www.cafamily.org.uk/
Cooley's Anemia Foundation (Thalassemia) http://www.thalassemia.org/
(The) Corneal Dystrophy Foundation
http://www.cornealdystrophyfoundation.org/html/cd_defined.html
CORE: Center for Organ Recovery and Education http://www.core.org/
Corneal Research Foundation of America http://www.cornea.org/
Corneal Dystrophy Foundation http://www.cornealdystrophyfoundation.org/
Costello Syndrome Family Network-United States http://www.costellosyndromeusa.org/
Creutzfeldt Jacob Disease Foundation http://www.cjdfoundation.org/
CurePSP Foundation for Progressive Supranuclear Palsy (PSP)/Corticobasal Degeneration (CBD)/and
Related Brain Diseases http://www.psp.org/
Cri du Chat (Cat Cry/5P Syndrome) http://www.fivepminus.org/; http://4p-supportgroup.org/
Cushing's Support and Research Foundation http://www.csrf.net/
Cutaneous Lymphoma Foundation http://www.clfoundation.org/
Cutis Laxa Internationale (Available in English, French, Spanish, and German)
http://asso.orpha.net/cutislax/
Cystinosis Research Network http://www.cystinosis.org/
Cystinosis Research Foundation http://www.natalieswish.org/
Cystinosis Research Network http://www.cystinosis.org/
Daily Strength Support Groups http://www.dailystrength.org/support-groups
Dancing Eye Syndrome Support Trust (Opsoclonus Myoclonus) http://www.dancingeyes.org.uk/
Dandy-Walker Alliance http://www.dandy-walker.org/
DanonDisease.org http://www.danondisease.org/
Danon Disease Support Network http://www.danon-disease-support.webs.com/
Dartmouth-Hitchcock Health Information
http://patients.dartmouth-hitchcock.org/health_information.html
DEBRA of America (Dystrophic Epidermolysis Bullosa http://www.debra.org/
DEBRA International http://www.debra-international.org/
Dercum Society http://www.dercumsociety.com
Desmoid Tumor Research Foundation http://www.dtrf.org/
Developmental Delay Resources (DDR) http://www.devdelay.org/
Devic's Syndrome (Neuromyelitis Optica) http://www.swmssupport.org/
(What Is) Devic's Disease UK http://www.devic.org.uk/
Diabetes UK  http://www.diabetes.org.uk/About_us/Contact_us/
Diamond Blackfan Anemia and You  http://www.diamondblackfananemia.com/
Directory of Health Organizations Online (DIRLINE)  http://dirline.nlm.nih.gov/
Disease InfoSearch  http://www.diseaseinfosearch.org/site/index
Disorders of Chromosome 16 Foundation  http://www.trisomy16.org/
Divry-Van Bogaert Syndrome  http://www.rightdiagnosis.com/medical/divry_van_bogaert_syndrome.htm
DNAandU  http://www.dnaandu.org/
Dravet.org  https://dravet.org/
Dravet Syndrome Foundation  http://www.dravetfoundation.org/
Duchenne Connect  https://www.duchenneconnect.org/
Dysautonomia Foundation, Inc  http://www.familialdysautonomia.org/
Dysautonomia Youth Network of America  http://www.dynainc.org/
Dystrophic Epidermolysis Bullosa Research Association of America (DEBRA)  http://www.debra.org
EB (Epidermolysis Bullosa) Medical Research Foundation  http://www.ebkids.org/
ECG Global Alliance (Erdheim-Chester Disease)  http://www.erdheim-chester.org/
Ehlers-Danlos National Foundation  http://edfn.org/
Ehlers Danlos Foundation of New Zealand  http://www.edfnz.org.nz/
Ehlers Danlos Support UK  http://www.ehlers-danlos.org/
ELA-European Leukodystrophy Association  http://www.ela-asso.com
eOrthopod (Blount's Disease)  http://www.eorthopod.com/content/blounts-disease-in-children-and-adolescents
Encephalitis Ireland  http://www.encephalitisireland.ie/
Encephalitis Society (Based in UK)  http://www.encephalitis.info/
Ependy Parents (Ependymoma)  http://www.ependyparents.org
EpendyKids  http://ependykids.com/
Epilepsy Foundation  http://www.epilepsyfoundation.org
(The)Erythromelalgia Association  http://www.erythromelalgia.org/
European Alliance of Neuromuscular Disorders Associations  http://www.eamda.eu/
Euro-Ataxia (European Federation of Hereditary Ataxias)  http://www.euro-ataxia.eu/
European Chromosome 11 Network  http://11g.chromosome11.eu/
European Skeletal Dysplasia Network  http://www.esdn.org/eug/Home
Eurordis : Rare Disease Patient Groups in the European Union  http://www.eurordis.org/what-we-do
http://www.eurordis.org/specialized-social-services
Evans Syndrome Community Network  http://evanssyndrome.blogspot.com/
Evans Syndrome Support and Research Group  http://www.evanssyndrome.org/
Experience Project: I Have a Rare Disease (searchable, helps create patient sharing)  http://www.experienceproject.com/groups/Have-A-Rare-Disease/34120
Fabry Support and Information Group  http://www.fabry.org/
(The) Facial Paralysis Foundation [http://www.facialparalysisinstitute.com/foundation/]
Families of SMA (Spinal Muscular Atrophy) [http://www.fsma.org/]
Families of SMA (Spinal Muscular Atrophy) International [http://www.fsma.org/FSMACommunity/Chapters/InternationalAffiliates/]
Families of Spinal Muscular Atrophy Canada [http://www.curesma.ca/]
Family Caregiver Alliance [http://www.thefamilycaregiver.org/]
Family Connect (Children with Visual Impairments) [http://www.familyconnect.org/]
Family Support Network [http://www.familysupportnetwork.org/] (helps with disabilities)
Fanconi Anemia Research Fund, Inc [http://www.fanconi.org/]
Fetal Hope Foundation (Amniotic Band Syndrome) [http://www.fetalhope.org/]
FEVR.net (Familial Exudative Vitreoretinopathy) [http://www.fevr.org/]
Fibrous Dysplasia Foundation [http://www.fibrousdysplasia.org/]
Fibromuscular Dysplasia Society of America [http://www.fmdsa.org/]
Fibrosing Mediastinitis [http://www.fibrosing-mediastinitis.com/]
Fibrous Dysplasia Online [http://www.dailystrength.org/c/Fibrous-Dysplasia/support-group]
Fight Colorectal Cancer [http://www.fightcolorectalcancer.org]
Fight SMA (Spinal Muscular Atrophy) [http://www.fightsma.org/]
FMF Montreal.org (Familial Mediterranean Fever) [http://www.fmfmontreal.org/]
FMF Community Online Support Groups [http://www.inspire.com/groups]
FOCUS Families (Optic Nerve Hypoplasia) [http://www.focusfamilies.org/]
FOCUS ON (Chronic Lymphocytic Leukemia) [http://www.focusoncll.org]
FOD Family Support Group (Fatty Oxidation Disorder) [http://www.fodsupport.org/]
FSH Society, Inc. (Facioscapulohumeral MD) [http://www.fshsociety.org/]
FSHD Global Research Foundation [http://www.fshdglobal.org/]
Foundation for Fighting Blindness [http://www.blindness.org/]
Foundation for Angelman Syndrome Therapeutics [http://www.cureangelman.org/]
Foundation for Angelman Syndrome Therapeutics [http://www.cureangelman.org.au/]
Foundation for Children with Atypical Hemolytic Uremic Syndrome [http://www.atypicalhus.ning.com/]
Foundation for Ichthyosis and Related Skin Types (FIRST) [http://www.firstskinfoundation.org/]
Foundation for Prader-Willi Research [http://www.fpwr.org/]
Foundation for Retinal Research (Leber’s Congenital Amaurosis) [http://www.tfrr.org/]
Foundation for Sarcoïdosis Research [http://www.stopsarcoïdosis.org/]
Freeman-Sheldon Research Group, Inc. (Former F-S Parent Support Group) [http://www.fsrgroups.org/]
Friedreich’s Ataxia Parents’ Group [http://www.faparents.org/]
Friedreich’s Ataxia Research Alliance (FARA) [http://www.curefa.org]
Friends of ET Research (Essential Thrombocythemia) [http://www.guidestar.org/organizations/06-1608492/friends-essential-thrombocythemia.aspx#]
Friends of FSH Research (Facioscapulohumeral MD) [http://www.fshfriends.org/]
Friends of Landau-Kleffner Syndrome (FOLKS, UK registered, also see aussiefolks) [http://www.friendsoflks.com/]
Frontotemporal Dementia Caregiver Support Center (Pick’s Disease) [http://www.ftdsupport.com/]
Frontotemporal Dementia Caregiver Support Center (Corticobasal Degeneration) [http://ftdsupport.com/typeof-cbd.htm]
Galactosemia Foundation [http://galactosemia.org/]
Galactosemia Support Group [http://www.dailystrength.org/c/Galactosemia/support-group]
Gastroparesis and Dysmotilities Association (GPDA) [http://www.digestedistress.com/]
Gastroschisis Exomphalos Extrophies Parents Support (GEEPS)  http://www.geeps.co.uk/
Gastroschisis Support Group Australia  http://www.gastroschismiracles.webs.com/
GBS/CIDP Foundation International (Guillain-Barre Syndrome; Chronic Inflammatory Demyelinating Polyneuropathy)  http://www.gbs-cidp.org/
Genetic Alliance  http://www.geneticalliance.org
Genetic Alliance UK  http://www.geneticalliance.org.uk/
Genetic and Rare Diseases Information Center (GARD)  http://rarediseases.info.nih.gov/GARD/
Genetic/Rare Conditions: National/International Groups  http://www.kumc.edu/gec/support/grouporg.html
GIST Cancer Research Fund  (Gastrointestinal Stromal Tumor)  http://www.gistinfo.org/
Glaucoma Association  http://www.glaucoma.org/
Glaucoma Research Foundation  http://www.glaucoma.org/
Glaucoma Research Society of Canada  http://www.glaucomaresearch.ca/
Global CDH (Congenital Diaphragmatic Hernia)  http://globalcdh.org/Home.html
(The)Global Genes Project  http://globalgenes.org/
Global Foundation for Peroxisomal Disorders  http://www.thegfpd.org/
Global Organization for Lysosomal Diseases (GOLD)  http://www.goldinfo.org/
Graves’ Disease and Thyroid Foundation  http://www.gdtf.org/
Guthy-Jackson Charitable Foundation (Neuromyelitis Optica)  http://www.guthyjacksonfoundation.org/
Gynecomastia  http://www.mdjunction.com/forums/gynecomastia-discussions
Haily-Haily Disease Society  http://www.haileyhailey.com/  (Site is blocked, see Genetic Alliance for access)
Hailey’s Wish (Alper’s Syndrome and Mitochondrial Diseases in Children)  http://www.haileyswish.org/
Health Information Resource Database (National Health Information Center)  http://health.gov/nhic/NHICScripts/Hitlist.cfm?Keyword=patient advocacy
Health Link British Columbia  http://www.healthlinkbc.ca
Health Support Groups/Conditions and Diseases/Genetic Disorders  http://www.dmoz.org/Health/Support_Groups/Conditions_and_Diseases/Genetic_Disorders/
Healthy Smiles, Healthy Children Foundation  http://www.aapd.org/foundation/
Heart and Hands: Loin Pain Hematuria Syndrome  (Google for Various Associated Sites)
HelpMeSee (Blind Children and Adults)  http://www.HelpMeSee.org
Hemophilia Federation of America  http://hemophiliafed.org/
Hereditary Disease Foundation  http://www.hdfoundation.org
Hereditary Leiomyomatosis and Renal Cell Cancer Family Alliance  http://www.hlrcinfo.org/
Hereditary Neuropathy Foundation  http://www.hnf-cure.org/
Hereditary Spherocytosis Support Group  (Via Genetic Alliance, also see Patient.co.uk)
International Foundation for CDKL5 (Cyclin-Dependent Kinase-Like 5) Research  
http://www.cdkl5.com/
International Foundation for Functional Gastrointestinal Disorders  
http://www.iffgd.org/
International Foundation for Marfan Syndrome Organizations  
http://www.marfanworld.org/
International Foundation for Optic Nerve Disease (Leber Hereditary Optic Nerve)  
http://www.ifond.org/lhon.php3
International Glaucoma Association  
http://www.glaucoma-association.com/
International Huntington Association  
http://www.huntington-assoc.com/
International Hyperhidrosis Society  
http://www.sweathelp.org/
International Myeloma Foundation  
http://www.myeloma.org/
International Myotonic Dystrophy Family Foundation  
http://www.myotonic.org/
International Network of Ataxia Friends  
http://www.internafl.org/
International Prader-Willi Syndrome Organisation  
http://www.ipwso.org
International Patient Organization for Patients with Primary Immunodeficiencies  
http://www.ipopi.org/
International Premature Ovarian Failure Association  
http://www.ipofa.org/
International Pemphigus and Pemphigoid Foundation  
http://www.pemphigus.org/
International Rett Syndrome Foundation  
http://www.rettsyndrome.org/
International Scleroderma Network  
http://www.sclero.org/
International Society for Infectious Diseases  
http://www.isid.org/
International Society for Pediatric and Adolescent Diabetes  
http://www.ispad.org/
International Still’s Disease Foundation  
http://www.stillsdisease.org/
International Susac’s Syndrome Foundation  
http://www.ucalgary.ca/susac/foundall
International WAGR Syndrome Association  
http://www.wagr.org/
Intersex Society of North America (Swyer Syndrome)  
http://www.isna.org/faq/conditions/swyer
Interstitial Cystitis Association  
http://www.icHELP.org/
Interstitial Cystitis Network (World Center)  
http://www.ic-network.com/world/
Intractable Childhood Epilepsy (ICE) Alliance  
http://www.ice-epilepsy.org/about.htm
Intrahepatic Cholestasis of Pregnancy  
http://www.icpcare.org
Iron Disorder Institute  
http://www.irondisorders.org/
Italian Registry of MYH9-Related Disease  
http://wwwregistromyh9.org/English_version/
ITP Foundation (Immune Thrombocytopenic Purpura)  
http://www.itpfoundation.org/
Jain Foundation, Inc. (Dysferlinopathy, Miyoshi Myopathy)  
http://www.jain-foundation.org/
Jeanette’s APECED (Autoimmune Polyendocrine Syndrome) (NZ)
Jeffrey Modell Foundation/National Primary Immunodeficiency Resource Center  
http://www.info4pi.org/jmf/
Jeune Syndrome Information and Support Network  
http://www.geneticalliance.org/organization/jeune-syndrome-information-and-support-network
Jewish Genetic Disease Consortium  
http://www.jewishgeneticdiseases.org/
Johns Hopkins University School of Medicine  
http://www.hopkinsmedicine.org/som/ (Search Patient Support Groups)
Joshua Frase Foundation (Myotubular Myopathy)  
http://www.joshuafrase.org/
Joubert Syndrome Foundation & Related Disorders  
http://www.jsrdf.org/
Justin E. Rodgers Foundation for Lemierre’s Awareness, Inc.  
http://www.lemierresyndrome.com/
Juvenile Diabetes Research Foundation  
International  
http://www.jdrf.org/files/General_Files/Life_with_Diabetes/lifenewsletter/LWD_Nov08.pdf
Juvenile Scleroderma Network  
http://www.jsdn.org/
Kabuki Syndrome Network  
http://kabukisyndrome.com/
Kartagener’s Syndrome  http://www.patient.co.uk/doctor/Kartagener’s-Syndrome.htm
Kartagener’s Syndrome and Primary Ciliary Dyskinesia
Kawasaki Disease Foundation  http://www.kdfoundation.org/
Kawasaki Support Group UK  http://www.kssg.org.uk/
Kearnes-Sayre Syndrome  http://www.patient.co.uk/selfhelp.asp
Kennedy’s Disease Association  http://www.kennedysdisease.org/
KickAS.org (Ankylosing Spondylitis Support)  http://www.kickas.org/
Kidney Cancer Association  http://www.kidneycancer.org/
Kids v Cancer (Metastatic Medulloblastoma)  http://www.kidsvcancer.org/
Klebsiella Pneumoniae  http://klebsiella-pneumoniae.org/
Klinefelter Syndrome Support Group  http://klinefeltersyndrome.org/
(The)Klippel-Trenaunay Syndrome Support Group  http://k-t.org/
Kure It  http://www.kureit.org  (Rare and common cancers)
La Leche League International
LAM Action  http://lamaction.org/  (UK group)
Lam Foundation  http://www.thelamfoundation.org
Laryngeal Cleft Kids  http://laryngealcleftkids.ning.com/
Laryngeal Cleft European Support Group  http://laryngeal-cleft-support-group.ning.com/
Laurence-Moon Bardet-Biedl Society UK (LMBB Syndrome)  http://www.lmbbs.org.uk/
LDNZ (Lysosomal Diseases New Zealand  http://www.ldnz.org.nz/
Les Turner ALS Foundation, Ltd  http://www.lesturnerals.org/
Let’s Face It University of Michigan/Craniofacial Conditions  http://desica.dent.umich.edu/faceit/
Leukemia and Lymphoma Society  http://www.leukemia.org/
Lewy Body Dementia Association  http://www.lbda.org/
Lewy Body Dementia Toronto Dementia Network  http://www.dementiotoronto.org/dementias/LewyBody.htm
LGS (Lennox-Gastaut Syndrome) Foundation  http://www.lgsfoundation.org/
Life Raft Group (Gastrointestinal Stromal Tumor)  http://www.liferafgroup.org/
Lighthouse International  http://www.lighthouse.org/  (Search Rare Conditions)
Limb Differences (International)  http://limbdifferences.org/
Lissencephaly Contact Group  http://www.lissencephaly.org.uk
Lipid Storage Disorders Patient Support Groups  http://www.mdjunction.com/lipid-storage-disorders
Lipoma Support Group  http://www.mdjunction.com/lipoma
Little People of America, Inc. (Short Stature)  http://www.lpaonline.org/
Living with CIDP (Chronic Inflammatory Demyelinating Polyneuropathy)  http://www.livingwithcidp.org/
Living with Eagle Syndrome  http://www.livingwitheagle.org/
Living with Thrombophilia (Factor V Leiden, FVL)  http://www.fvleiden.org/
Living with Trisomy 13  http://www.livingwithtri13.org/
LMSarcoma Direct Research Foundation (Leiomyosarcoma)  http://www.lmsdr.org/
Locks of Love  http://www.locksoflove.org/
Loeys-Dietz Syndrome Foundation [http://www.loeysdietz.org/]
Loeys-Dietz Syndrome Foundation-Canada [http://www.loeysdietz.org/canada.php]
Lowe Syndrome Association [http://www.lowesyndrome.org/]
 Lupus Foundation of America [http://www.lupus.org]
Lymphangiomatosis & Gorham’s Disease [http://www.lgdalliance.org/]
Lymphoedema Support Network (LSN) [http://www.lymphoedema.org/]
Lymphoma Research Foundation [http://www.lymphoma.org/]
Lynch Syndrome International [http://www.lynchcancers.com/]
Lysosomal Disease Network (Lysosomal Storage Disease) [http://www.lysosomaldiseasenetwork.org/]
Macula.ORG (Association for Macular Diseases) [http://www.macula.org/]
Macular Degeneration Foundation [http://www.eyesight.org/]
Macular Disease Society [http://www.maculardisease.org/]
Madison’s Foundation [http://www.madisonsfoundation.org/]
MAGNUM (The National Migraine Association) [http://www.migraines.org/]
MACS-The Micro and Anophthalmic Children’s Society [http://www.macs.org.uk/]
Malia’s Cord Foundation [http://www.cordfoundation.org]
Malignant Hyperthermia Association of the United States (MHAUS) [http://patients.mhaus.org/]
Maple Syrup Urine Disease Family Support Group (MSUD) [http://www.msud-support.org/]
March of Dimes Birth Defects Foundation [http://www.marchofdimes.com]
Marfan Association UK [http://www.marfan-association.org.uk/]
Marigold Foundation [http://marigoldfoundation.org/] (Myotonic Muscular Dystrophy-Canadian)
Marshall-Smith Syndrome (MSS) Research Foundation [http://www.marshallsmith.org/]
Mastocytosis Society, Inc. [http://www.tmsforacure.org/]
M-CM Network (Macrocephaly-Capillary Malformation) [http://www.m-cm.net/]
MEBO Research [http://www.meboresearch.org/aboutmebo.html]
(The) Megan Foundation for Usher Syndrome [http://www.meganfoundation.org/usher-syndrome/]
Melorheostosis Association [http://www.melorheostosisassociation.org] (NIH need to allow this URL)
Menetrier’s Disease (Giant Hypertrophic Gastritis) [http://www.patient.co.uk/doctor/Menetrier’s-Disease.htm]
Mesothelioma Help Now [http://www.mesotheliomahelpnow.com/mesothelioma-support]
MdDS Balance Disorder Foundation (Mal de Debarquement Syndrome) [http://www.mddsfoundation.org/]
MD Junction Support Groups [http://www.mdjunction.com/support-groups]
MedicAlert Foundation [http://www.medicalert.org/]
MELAS: Experience Project [http://www.experienceproject.com/groups/Have-Melas-Syndrome/98678]
Meningitis Foundation of America [http://www.meningitis]
MHE Research Foundation (Multiple Hereditary Exostoses and Osteochondroma Syndrome) [http://www.mheresearchfoundation.org/]
Mental Health America [http://www.mentalhealthamerica.net]
Metabolic Disorders Support Group: Inspire [http://www.inspire.com/groups/metabolic-disorders/]
MHE Research Foundation (Multiple Hereditary Exostoses and Osteochondroma Syndrome) [http://www.mheresearchfoundation.org/]
Michael J. Fox Foundation (Parkinson’s Disease) [http://www.michaeljfox.org/]
MitoAction (Mitochondrial Disease) [http://www.mitoaction.org/]
Moebius Syndrome Foundation (STARS) [http://www.moebiussyndrome.com/]
Moebius Syndrome Support Network [http://www.wincom.net/moebius/]
Mollaret’s Meningitis Support Group [http://mollaretsmeningitus.ning.com/]
Motor Neurone Disease Association  http://www.mndassociation.org/
Mowat-Wilson Syndrome Support Group http://www.mowatwilsonsyndrome.org.uk/
MPN Education Foundation (Myeloproliferative Neoplasms) http://www.mpdinfo.org/
MPN Research Foundation (Myeloproliferative Neoplasms) http://www.mpnresearchfoundation.org/
Mucolipidosis Type IV Foundation, Inc. http://www.ml4.org/
Multiple Hereditary Exostoses (MHE) Patient Support (UK based) http://www.radix.net/~hogue/mhe.htm
Multiple Myeloma Research Foundation http://www.themrmf.org/
Multiple Sclerosis Association of America http://www.msassociation.org
Multiple Sclerosis Society http://www.nationalmssociety.org/index.aspx
Multiple Sclerosis Foundation http://www.msfocus.org/
Muscular Dystrophy Association http://www.mda.org/
Muscular Dystrophy Campaign http://www.muscular-dystrophy.org/
Muscular Dystrophy Family Foundation http://www.mdff.org/
Muscular Dystrophy Foundation http://www.myotonic.org/
My Child Without Limits (Developmental Delay, etc.) http://www.mychildwithoutlimits.org/
Myasthenia Gravis Foundation of America, Inc. http://www.myasthenia.org/
(My)Myelin Project for Research and Education http://www.myelin.org/
Myelofibrosis Research Foundation http://www.mpnresearchfoundation.org/Support-Groups
Myeloma Canada http://www.myelomacanada.ca
Myeloma UK http://www.myeloma.org.uk/
(My)Myelin Project http://www.myelin.org
(My)Myocarditis Foundation http://myocarditisfoundation.org/
MyHealthShare Community Center (CheckOrphan) http://myhealthshare.org/
Myositis Association http://www.myositis.org/template/page.cfm?id=2
Myotonic Dystrophy Foundation http://www.myotonic.org/
Myotonic Dystrophy Support Group http://www.myotoxicdystrophysupportgroup.org/
Nail Patella Syndrome Worldwide http://www.npsw.org/
Nathan's Battle Foundation (Late Infantile Batten Disease) http://www.nathansbattle.com/
National Adrenal Diseases Foundation http://www.nadf.us/
National Alliance for Breast Cancer Organizations http://www.looktothestars.org/
National Alliance for Eye and Vision Research http://www.eyeresearch.org/
National Alliance on Mental Illness http://www.nami.org/
National Alopecia Areata Foundation http://www.naaf.org
National Ankylosing Spodylitis Society UK http://www.nass.co.uk/
National Aphasia Association http://www.aphasia.org/
National Association for Continence http://www.nafc.org/
National Association for Pseudoxanthoma Elasticum http://www.pxenape.org/
National Association of the Deaf http://www.nad.org/
National Ataxia Foundation http://www.ataxia.org/
National Brain Tumor Society http://www.braintumor.org/
National Dysautonomia Research Foundation http://www.ndrf.org/
National Dystonia Research Foundation http://www.ndrf.org/
National Eosinophilia-Myalgia Syndrome Network http://www.nemsn.org/
National Fabry Disease Foundation http://fabrydisease.org/
National Foundation for Ectodermal Dysplasias http://www.nfed.org/
National Family Caregivers Association  http://www.nfcacares.org/
National Federation of the Blind  http://www.nfb.org/
National Foundation for Ectodermal Dysplasias  http://www.nfed.org/
National Foundation for Infectious Diseases  http://www.nfid.org/
National Fragile X Foundation  http://www.fragilex.org/
National Gaucher Foundation  http://www.gaucherdisease.org/
National Gaucher Foundation of Canada  http://www.gauchercanada.ca/
National Headache Foundation  http://www.headaches.org/
National Hemophilia Foundation  (Includes platelet function defects.)  http://www.hemophilia.org/
National Hydrocephalus Foundation  http://www.nhfonline.org/
National Infertility Association  http://www.resolve.org/
National Keratoconus Foundation  http://www.nkcf.org/
National Kidney Center  http://www.nationalkidneycenter.org
National LeioMyosarcoma Foundation  http://www.nlmsf.org/
National Lipedema Association  http://www.lipedema.org/  (Site being prepared) Also see https://www.giveback.org/cause/3542/National-Lipedema-Association-Inc.aspx
National Lymphedema Network  http://www.lymphnet.org
National Marfan Foundation  http://www.marfan.org/marfan/
National MPS Society(Mucopolysaccharidoses)  http://www.mpssociety.org/
National Neutropenia Network  http://www.neutropenianet.org/
National Organization for Albinism and Hyperpigmentation  http://www.albinism.org/
National Organization for Rare Diseases (NORD)  http://www.rarediseases.org/patient-orgs/current
National Organization of Disorders of the Corpus Callosum  http://www.nodcc.org/
National Organization of Vascular Anomalies  http://www.novanews.org/
National Osteonecrosis Foundation  http://www.nonf.org/
National Ovarian Cancer Coalition  http://www.ovarian.org/
National Pancreas Foundation  http://www.pancreasfoundation.org/
National Parkinson Foundation  http://www.parkinson.org/
National PKU Alliance  http://www.pkua.org/
National PKU News  (Organizations)  http://www.pkunews.org/support/groups.htm
National Primary Immunodeficiency Resource Center  http://www.info4pi.org/  (Common but with rare subsets)
National Psoriasis Foundation  http://www.psoriasis.org/
National Rehabilitation Information Center  http://www.naric.com/
National Respite Network and Resource Center  http://archrespite.org/
National Rosacea Society  http://www.rosacea.org/
National Reye’s Syndrome Foundation  http://www.reyessyndrome.org/
National Society for Phenylketonuria  http://www.nspku.org/
National Spasmodic Dysphonia Association (Laryngeal Dyskinesia)  http://www.dysphonia.org/
National Spasmodic Torticollis Association  http://www.torticollis.org/
National Spinal Cord Injury Association  http://www.spinalcord.org/
National Spinal Cord Tumor Association  http://www.spinalcordtumor.org
National Stroke Association  http://www.stroke.org/
(A)National Support Group for Arthrogryposis Multiplex Congenita (AVENUES)  http://www.avenuesforamc.com/
National Tuberous Sclerosis Alliance [http://www.tsalliance.org/index.aspx](http://www.tsalliance.org/index.aspx)
National Urea Cycle Disorders Foundation [Http://www.nucdf.org/](http://www.nucdf.org/)
NBIA Disorders Association (Neurodegeneration with Brain Iron Accumulation) [http://www.nbiadisorders.org/](http://www.nbiadisorders.org/)
(The)NephCure Foundation (Nephrotic Syndrome) [http://www.nephcure.org/](http://www.nephcure.org/)
Neutropenia Support Association, Inc. [http://www.neutropenia.ca/](http://www.neutropenia.ca/)
http://www.patient.co.uk/search.asp?searchterm=JADASSOHN (Tieche-Jadassohn Nevus)
NOMID Alliance (Cryoptrin-Associated Periodic Syndromes/Inflammatory Diseases) [http://www.nomidalliance.org/](http://www.nomidalliance.org/)
Nonketotic Hyperglycemia International Family Network
Noonan Syndrome Support Group Inc. [http://www.noonansyndrome.org](http://www.noonansyndrome.org)
NORD Rare Disease Support Community (Mucha-Habermann Disease) [http://www.inspire.com/groups/rare-disease/discussion/mucha-habermann-disease-1/](http://www.inspire.com/groups/rare-disease/discussion/mucha-habermann-disease-1/)
Obstetric Cholestasis Support [http://www.ocsupport.org/index.html](http://www.ocsupport.org/index.html)
Ocular Immunology and Uveitis Foundation [Http://www.uveitis.org/](http://www.uveitis.org/)
Ocular Melanoma Foundation [http://wwwocularmelanoma.org/](http://wwwocularmelanoma.org/) (Click on Patients)
Ocular Immunology and Uveitis Foundation (Panuveitis) [http://www.uveitis.org/](http://www.uveitis.org/)
Ohdo Syndrome Family Network
OrphaNet (Search portal for international patient organizations) [http://www.orpha.net/consor/cgi-bin/SupportGroup.php?lng=EN](http://www.orpha.net/consor/cgi-bin/SupportGroup.php?lng=EN)
Osteogenesis Imperfecta Foundation [http://www.oif.org/site/PageServer](http://www.oif.org/site/PageServer)
Pallister-Killian Syndrome [http://www.pkskids.net](http://www.pkskids.net)
PAN Research and Support Network (Polyarteritis Nodosa) [http://www.pansupportnetwork.org/](http://www.pansupportnetwork.org/)
Panuveitis (Description and Information) [http://www.panuveitis.com](http://www.panuveitis.com)
Parent Project Muscular Dystrophy  http://www.parentprojectmd.org/
Parents and Researchers Interested in Smith-Magenis Syndrome  http://www.prisms.org/
Parents of Blind Children http://www.nfb.org/parents-and-teachers
Parents of Infants and Children with Kernicterus (PICK Online)  http://www.pickonline.org/
(The) Romberg’s Connection (Parry Romberg Syndrome  http://www.therombergsconnection.com/
Parsonage Turner Syndrome  http://www.autoimmunitycommunity.org/
Patient.co.uk  http://www.patient.co.uk/ (Health Information/search rare diseases, directory)
Patient.co.uk Support Directory  http://www.patient.co.uk/support-directory.asp
Patients Connect  http://patients-connect.com/
Pedal with Pete (Cerebral Palsy)  http://pedal-with-pete.org/cerebral-palsy/
Pediatric Brain Tumor Foundation  http://www.pbtfus.org/
Pediatric Neurotransmitter Disease Association  http://www.pndassoc.org/
Pelizaeus-Merzbacher Disease Foundation  http://pmdfoundation.org/
Pemphigus and Pemphigoid Foundation (International)  http://www.pemphigus.org/
Periodic Paralysis Association  http://www.periodicparalysis.org/english/view.asp?x=1
Phelan-McDermid Syndrome Foundation  http://22q13.org/j15/
Picardi-lassueur-little Syndrome  
http://www.experienceproject.com/groups/Have-Picardi-lassueur-little-Syndrome/92364
Pick’s Disease (Helpguide.org)  http://www.helpguide.org/elder/picks_disease.htm
Pierre Robin Network  http://www.pierrerobin.org/
Pituitary Network Association  http://www.pituitary.org/intro.aspx  (Also Canada)
Pitt Hopkins Syndrome International Network  http://www.pitthopkins.org/
PKD Foundation  (Polycystic Kidney Disease)  http://www.pkdcure.org  (See also UK, Canada, Australia)
PKS Kids  (Pallister-Killian Syndrome)  http://www.pkskids.net/
PKU (Phenylketonuria) and Allied Disorders (Canadian)  http://www.canpku.org/
Platelet Disorder Support Association  http://www.pdsa.org/
PMP Research Foundation  http://www.pmpcure.org/
Poland Syndrome Support Group  http://www.pssgcharity.org/  (UK based)
Polio Experience Network (Post-Polio Syndrome) International on-line  http://www.polionet.org/
Polymyalgia Rheumatica: Experience Project (Juvenile)  
http://www.dailystrength.org/groups/polymyalgia-rheumatica/members
http://www.experienceproject.com/groups/Have-Polymyalgia-Rheumatica/99241
Polymyalgia Rheumatica: INSPIRE  https://www.inspire.com/conditions/polymyalgia-rheumatica/
Polymyositis and Dermatomyositis Support Group  
http://www.dailystrength.org/c/Polymyositis-and-Dermatomyositis/support-group
Post-Polio Health International  http://www.post-polio.org/
Potter Syndrome Support and Contact Group  
http://www.patient.co.uk/support/Potter’s-Syndrome-Support-and-Contact-Group.htm/
Prader-Willi Syndrome Association  http://www.pwsausa.org
Prevent Blindness America  http://www.preventblindness.org
Primary Ciliary Dyskinesia (PCD) Foundation  http://www.pcdfoundation.org/
Progeria Project Foundation  http://www.progeriaproject.com
Progeria Research Foundation, Inc. [http://www.progeriaresearch.org/]
Progressive Osseous Heteroplasia Association [http://www.pohdisease.org/]
Propionic Acidemia Foundation [http://www.pafoundation.com/]
Proteus Syndrome Foundation [http://www.proteus-syndrome.org/]
Proyecto pde un Deseo Mexico [http://iap.pideundeseo.org/]
Prune Belly Syndrome Network (PBSN) [http://www.prunebelly.org/]
PSC Partners Seeking a Cure [http://www.pscpartners.org/]
Pseudo Xanthoma Elasticum [http://www.pxe.org.uk/]
Pulmonary Fibrosis Foundation [http://www.lung.org/]
Pulmonary Hypertension Association [http://www.phassociation.org/]
Purine Research Society [http://www.purineresearchsociety.org]
Q Fever [http://www.patient.co.uk/doctor/Q-Fever/resources]
Qazi Markouizos Syndrome [http://www.experienceproject.com/groups/Have-Qazi-Markouizos-Syndrome/92171]
Quebec Platelet Disorder (Platelet Disorder Support Association) [http://www.pdsa.org/]
Rabies [http://www.dailystrength.org/c/Rabies/support-group]
http://www.patient.co.uk/health/Rabies-immunisation.htm
Rare Cancer Alliance [http://www.rare-cancer.org]
Rare Cancer Alliance/Patient.co.uk [http://www.patient.co.uk/support/Rare-Cancer-Alliance.htm]
Rare Cancers Europe [http://www.rarecancersurope.org]
Rare Genetic Skin Disease Center [http://www.geneskin.org/rare-genetic-skin-diseases.aspx]
Rare Connect: A Partnership of Eurordis and NORD [http://www.rareconnect.org/en]
RareShare [http://rareshare.org/]
R-E Children’s Project (Rasmussen Encephalitis) [http://www.rechildrens.org/blog/]
Recombinant Chromosome 8 Syndrome [http://www.rareconnect.org/en]
Recurrent Respiratory Papillomatosis Foundation [http://www.rrpf.org/]
Reed’s Syndrome (Check Orphan) [http://www.checkorphan.org/disease/reedsyndrome]
Relapting Polychondritis [http://www.patient.co.uk/doctor/Relapsing-Polychondritis.htm]
http://www.relapsingpolychondritis.org/
Renal Support Network [http://www.rsnhope.org/]
Renpenning Syndrome (Description and Resources) [http://pradais.blogspot.com/2012/07/genetics-home-reference-renpenning.html]
Reflex Sympathetic Dystrophy Syndrome Association of America [http://www.rsds.org/index2.html]
Retinitis Pigmentosa [http://www.galloways.org.uk/eyeinformation/eyetab06.html]
Rett Syndrome Foundation International [http://www.rettsyndrome.org/]
Ring Chromosome 22 [http://www.chromodisorder.org/CDO/General/IntroToChromosomes.aspx]
Ringed Hair Dysplasia (Dermatology Interest Group Association) [http://www.derminterest.org/phpbb3/viewtopic.php?f=1&t=584]
Robinow Syndrome Foundation  http://www.robinow.org/
Rocky Mountain Spotted Fever
https://my.advocatehealth.com/public/healthresearch/content_display_full.cfm?doc_id=P02538
http://www.mdjunction.com/rocky-mountain-spotted-fever
(The)Romberg’s Connection (Parry Romberg Syndrome) (International)
http://www.therombergsconnection.com/
Rothman-Thomson Syndrome Foundation  http://rtsplace.org/
Rotor’s Syndrome http://www.patient.co.uk/search.asp?searchterm=ROTOR+SYNDROME
Rubella http://www.mdjunction.com/forums/rubella-discussions/general-support
Rubinstein-Taybi Parent Group http://www.rubinstein-taybi.org/
Russell-Silver Syndrome Advocate http://rssadvocate.wordpress.com/
SADS Foundation (Sudden Arrhythmia Death Syndrome)  http://www.sads.org/StopSADS
Saethre-Chotzen Syndrome Patient Support Group
http://www.dailystrength.org/c/saethre-chotzen-syndrome/support-group
Sandhoff Disease Patient Support Group http://www.mdjunction.com/sandhoff-disease
Schimke Syndrome Patient Support Group
Schizencephaly Patient Support Group http://schizkidzbuddies.com/
http://www.patient.co.uk/leaflets/schizencephaly.htm
Scleroderma Society of Canada  http://www.scleroderma.ca/
Scleroderma Research Foundation http://www.srfcure.org/
Scleromyxedema Patient Support Group http://www.scleromyxedema.net/
Scoliosis Research Society http://www.srs.org/
SCOT Deficiency (Succinyl-CoA :3 ketoacid transferase deficiency)
http://www.diseaseinfossearch.org/SCOT+deficiency/6468; Also see OrphaNet
Share & Care (Cockayne’s Syndrome) Network http://www.cockaynesyndrome.net/main/
Shwachman-Diamond Syndrome Foundation http://www.shwachman-diamond.org/
Sclerosing Mesenteritis Supp http://health.groups.yahoo.com/group/panniculitis/
http://health.groups.yahoo.com/group/InternationalMesentericPanniculitisSociety/
Seplapterin Reductase Deficiency http://www.pndassoc.org/  (Pediatric Neurotransmitter Disease Association)
Septo-Optic Dysplasia patient support (See Focus Families:  http://www.focusfamilies.org/)
Serpiginous Choroiditis http://www.rightdiagnosis.com/s/serpiginous_choroiditis/intro.htm  (Right Diagnosis)
Severe Combined Immunodeficiencies (SCID) Patient Support http://www.scid.net/
Sezary Syndrome http://www.clfoundation.org/sites/default/files/content/Fact%20Sheet_SS.pdf
(Cutaneous Lymphoma Foundation)
Sheehan’s Syndrome (VHL Family Alliance)
http://www.inspire.com/groups/vhl-family-alliance/discussion/sheehans-syndrome/
SHORT Syndrome patient support http://www.lpa.org  (Little People of America, Inc.) Also search www.orpha.net for SHORT Syndrome
Sialadentis, Sialadosis patient support http://www.patient.co.uk/leaflets/sialadenitis.htm
Sialic Acid Storage Disorders (See metabolic and lysosomal diseases organizations)
Siderblastic Anemias http://www.medscape.com/  (Search for specific information)
Silicosis patient support http://www.medhelp.org  (Search condition); Also
Sinninger Merten Syndrome (Ectodermal Dysplasia)
[https://www.caring4dermatology.com/go/community/tools/knowledgebase/](https://www.caring4dermatology.com/go/community/tools/knowledgebase/)
Sjogren’s World (chat rooms/message boards) [http://www.sjogrensworld.org](http://www.sjogrensworld.org)
Slovakian Patient Alliance for Rare Diseases [http://www.sazch.sk/](http://www.sazch.sk/) (Not Translated)
Sneddon’s Foundation (Sneddon’s Syndrome) [http://www.sneddonsyndrome.org/](http://www.sneddonsyndrome.org/)
Spitz Nevus Patient Support (DermNet NZ) [http://www.dermnetnz.org/lesions/spitz-naevus.html](http://www.dermnetnz.org/lesions/spitz-naevus.html)
Spondylitis Association of America [http://www.spondylitis.org/](http://www.spondylitis.org/)
Stargardt Syndrome Patient Support (See Lighthouse International and Foundation for Fighting Blindness)
Stickler Involved People [http://www.sticklers.org/sip2/](http://www.sticklers.org/sip2/)
Stiff Person Syndrome (International) [http://www.eurordis.org/content/stiff-man-syndrome-still-dancing-inside](http://www.eurordis.org/content/stiff-man-syndrome-still-dancing-inside)
Stone Circle of Friends (Myotonic Muscular Dystrophy) [http://www.stonecircleoffriends.com/](http://www.stonecircleoffriends.com/)
Sturge-Weber Foundation UK [http://www.sturgeweber.org.uk](http://www.sturgeweber.org.uk)
Sturge-Weber Foundation (Canada), Inc. [http://www.sturge-weber.ca/](http://www.sturge-weber.ca/)
Support Groups for Patients with Rare Cancers [http://www.ask.com/web?qsrc=4018&o=102858&l=dir&q=Support+Groups+for+Patients+with+Rare+Cancers&oo=0](http://www.ask.com/web?qsrc=4018&o=102858&l=dir&q=Support+Groups+for+Patients+with+Rare+Cancers&oo=0)
Support for Disorders of Chromosome 22 (Cat’s Eye Syndrome) [http://www.c22c.org/ces.htm](http://www.c22c.org/ces.htm)
Support Links for Parents and Patients (Variety of Diagnoses Resource) [http://www.allkids.org/body.cfm?id=569](http://www.allkids.org/body.cfm?id=569)
Taiwan Foundation for Rare Disorders [http://www.tfrd.org.tw/english/](http://www.tfrd.org.tw/english/)
Tangier Disease [http://www.mdjunction.com/tangier-disease](http://www.mdjunction.com/tangier-disease)
TAR Syndrome Support Group http://www.ivh.se/TAR/
Tarlov Cyst Association http://www.tarlovcyst.net/
Tay-Sachs Disease Support Group http://www.mdjunction.com/tay-sachs-disease
Testicular Cancer Society http://www.testicularcancersociety.org/
Theodor Hertz Goodman Syndrome http://www.rightdiagnosis.com/medical/theodor_hertz_goodman_syndrome.htm
Tieche-Jadassohn Nevus Patient Support Groups (See Nevus) http://www.nevus.org/
TNA-The Facial Pain Association http://www.fpa-support.org/
(I Have)Transient Global Amnesia http://www.experienceproject.com/groups/Have-Transient-Global-Amnesia/91337/
Transverse Myelitis Association http://myelitis.org/
Treachers Collins Family Support Group http://www.treachercollins.net/
TREAT-NMD(Neuromuscular Network) http://www.treat-nmd.eu/
Trisomy 18 Foundation http://www.trisomy18.org
Tuberous Sclerosis Alliance http://www.tsalliance.org/
Turner Syndrome Foundation http://www.turnersyndromefoundation.org/
Turner Syndrome Society of the United States http://www.turnersyndrome.org/
Tyrosinemia Support Group http://www.dailystrength.org/c/Tyrosinemia/support-group;
https://www.counsyl.com/diseases/tyrosinemia-type-i/
United Leukodystrophy Foundation http://ulf.org/
United Mitochondrial Disease Foundation http://www.umdf.org
United Pompe Foundation http://www.unitedpompe.com/
United Spinal Association? http://www.unitedspinal.org (spinal injuries, disabilities and diseases)
Unverricht Lundborg Disease http://www.orpha.net/consor/cgi-bin/OC_Exp.php?Lng=EN&Expert=308
Upington Disease http://www.checkorphan.org/disease/upington-disease
Upton Young Syndrome http://www.rightdiagnosis.com/u/upton_young_syndrome/intro.htm
U.S. Hereditary Angioedema Association http://www.haea.org/about/
Van Den Bosch Syndrome http://www.rightdiagnosis.com/v/van_den_bosch_syndrome/intro.htm
Vascular Birthmarks Foundation http://birthmark.org/
Vascular Web (Mesenteric Ischemia) http://www.vascularweb.org/vascularhealth/Pages/mesenteric-ischemia.aspx
Vasculitis Foundation http://www.vasculitisfoundation.org/
Vasculitis Foundation (Takayasu’s Arteritis) http://www.vasculitisfoundation.org/education/forms/takayasus-arteritis/
Vasculitis Foundation Canada http://www.vasculitis.ca/
Vazquez Hurst Soto’s Syndrome
http://www.rightdiagnosis.com/v/vasquez_hurst_sotos_syndrome/intro.htm
Velo-Cardio-Facial Education Foundation http://www.vcfsef.org/
Vestibular Disorders Association http://vestibular.org/ (see also Australian and Canadian associations)
Von Hippel-Lindau (VHL) Syndrome http://www.vhl.org/
Wagner Syndrome http://www.wagnersyndrome.eu/
Waldmann Disease http://www.rightdiagnosis.com/w/waldmann_disease/intro.htm
(Jewish Genetic Disease Mazor Guide)
Walker Dyson Syndrome http://www.rightdiagnosis.com/w/walker_dyson_syndrome/intro.htm
Watson Syndrome (Neurofibromatosis Type 1)
http://www.rightdiagnosis.com/medical/watson_syn.htm
We Care: MLD (Metachromatic Leukodystrophy) Foundation http://www.mldfoundation.org/
WeMove (for movement disorders worldwide) http://www.wemove.org/
Wendt Center for Loss and Healing http://wendtcenter.org/
Wide Smiles http://www.widesmiles2.org/
Williams Syndrome Association http://www.williams-syndrome.org/
Wilson’s Disease Association International http://www.wilsonsdisease.org/
Windows of Hope Project (Pierson Syndrome)
http://www.wohproject.org/Disorders/a-z/pierson-syndrome-1/pierson-syndrome
Wisconsin ME/CFS Association, Inc.? http://www.wicfs-me.org/
Worldwide Society of Wolfram Syndrome Families http://www.wolframsyndrome.org/
World Craniofacial Foundation http://www.worldcf.org/
World Health Organization (WHO) Patient Support Groups Genome Resources
Worldwide Lichen Sclerosus Support http://lichensclerosus.org/
Xanthinurea (Information) http://emedicine.medscape.com/article/984002-overview#showall
XP Family Support Group (Xeroderma Pigmentosum) http://www.xpfamilysupport.org/
XLH Network (X-Linked Hypophosphoremia) http://xlhnetwork.org/
Yaws and Other Endemic Treponematoses (World Health Organization) http://www.who.int/yaws/en/
Yolk Sac Tumor http://www.patient.co.uk/doctor/Testicular-Tumours.htm
Yunis Varon Syndrome
4214&ar_uid=5D5D0C61-AD0C-1E9F-832E-B66AAD6B987&click_id=11F6FCEB-D7D1-49D6-9179-E9C7CCB376C0
Zadik Barak Levin Syndrome
Zap-70 Deficiency (UpToDate) http://www.uptodate.com/contents/zap-70-deficiency
Zazam Sheriff Phillips Syndrome
http://www.checkorphan.org/research/view/zazam-sheriff-phillips-syndrome/page/1
Zellweger Baby Support Network http://zbsn.org/
Zellweger Support Group Indian Patient Foundation
http://www.patient.org.in/group/zellwegersyndrome
Zellweger Syndrome Support Group Daily Strength
http://www.dailystrength.org/c/Zellweger-Syndrome/support-group
Zlotogora Syndrome http://www.experienceproject.com/groups/Have-Zlotogora-Syndrome/90875