

**List of organizations from the Genetic and Rare Diseases (GARD) Information Center
3/12/2015**

Resource Name:	Resource URL:
1 in 9: The Long Island Breast Cancer Action Coalition	http://www.1in9.org
11q Research and Resource Group	http://www.11qusa.org
17q21.31 Research Project	http://www.17q21.com/en/index.php
1p36 Deletion Support & Awareness	http://www.1p36dsa.org
22q11 Ireland	http://www.22q11ireland.org
22qcentral.org	http://22qcentral.org
2q23.org	http://2q23.org/
4p- Support Group	http://www.4p-supportgroup.org/
4th Angel Mentoring Program	http://www.4thangel.org
5p- Society	http://www.fivepminus.org
A Foundation Building Strength	http://www.buildingstrength.org
A National Support group for Arthrogryposis Multiplex Congenita (AVENUES)	http://www.avenuesforamc.com
A Place to Remember	http://www.aplacetoremember.com/
A Twist of Fate-ATS	http://www.atwistoffate-ats.com/
Aarons Ohtahara	http://www.ohtahara.org/
About Special Kids	http://www.aboutspecialkids.org/
AboutFace International	http://aboutface.ca/
AboutFace USA	http://www.aboutfaceusa.org
Accelerate Brain Cancer Cure	http://www.abc2.org
Accelerated Cure Project for Multiple Sclerosis	http://www.acceleratedcure.org
Accord Alliance	http://www.accordalliance.org/
Achalasia 101	http://achalasia.us/
Acid Maltase Deficiency Association (AMDA)	http://www.amda-pompe.org
Acoustic Neuroma Association	http://anausa.org/
Action to Cure Kidney Cancer	http://www.ackc.org/
Addison's Disease Self Help Group	http://www.addisons.org.uk/
Adenoid Cystic Carcinoma Organization International	http://www.accoi.org/
Adenoid Cystic Carcinoma Research Foundation	http://www.accrf.org/
Advocacy for Neuroacanthocytosis Patients	http://www.naadvocacy.org
Advocacy for Patients with Chronic Illness, Inc.	http://www.advocacyforpatients.org
AFE Foundation	http://www.afesupport.org

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AHC Association of Iceland	http://.www.ahc.is
AHC Federation of Europe	http://www.ahcfe.eu
Aicardi Syndrome Foundation	http://www.aicardisyndrome.org
AISDSD Support Group	http://www.aisdsd.org
AIS-DSD Support Group	http://www.aisdsd.org/
AKU Society	http://www.alkaptonuria.info/
AKU Society of North America	http://www.akusocietyna.org/
Alagille Syndrome Alliance	http://www.alagille.org
Albinism Fellowship	http://www.albinism.org.uk
ALD Life	http://www.aldlife.org/
Alex's Lemonade Stand Foundation	http://www.alexlemonade.org/
Alianza Iberoamericana de Enfermedades Poco Frecuentes	http://aliber.org/
Allergy & Asthma Network Mothers of Asthmatics	http://www.aanma.org
Alliance for Cryoglobulinemia	http://allianceforcryo.org/
Alliance for Lupus Research	http://lupusresearch.org/
Alopecia Support Group	http://www.alopeciasupport.org/
Alopecia World website	http://www.alopeciaworld.com
Alpha-1 Advocacy Alliance	http://www.alpha1advocacy.org
Alpha-1 Association	http://www.alpha1.org/
Alpha-1 Awareness UK	http://www.alpha1awareness.org.uk
Alpha-1 Canada	http://www.alpha1canada.ca
Alpha-1 Foundation	http://www.alpha-1foundation.org/
Alpha-1 UK Support Group	http://www.alpha1.org.uk
Alport Syndrome Foundation	http://www.alportsyndrome.org
Alport Syndrome Hope for the Cure Foundation	http://www.hopeforthecure.org
ALS Puerto Rico Support	http://alsprsupportgroup.ning.com/
Alstrom Syndrome International	http://www.alstrom.org
Alternating Hemiplegia of Childhood Foundation (AHCF)	http://www.ahckids.org
Alveolar Capillary Dysplasia Association	http://www.acd-association.com
Alzheimer's Drug Discovery Foundation (formerly, Institute for the Study of Aging)	http://www.alzdiscovery.org
Alzheimer's Association	http://www.alz.org
Alzheimer's Disease Education and Referral Center (ADEAR)	http://www.nia.nih.gov/alzheimers

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Alzheimer's Foundation of America	http://www.alzfdn.org
AMC Cancer Research Center	http://www.amc.org/
AMD Alliance International	http://www.amdalliance.org
American Academy of Allergy Asthma and Immunology	http://www.aaaai.org/home.aspx
American Academy of Dermatology	http://www.aad.org/
American Academy of Ophthalmology	http://www.aao.org/
American Academy of Oral & Maxillofacial Pathology (AAOMP)	http://www.aaomp.org
American Academy of Orthopaedic Surgeons	http://www.aaos.org/
American Academy of Podiatric Sports Medicine	http://www.aapsm.org/
American Academy of Pediatrics	http://www.aap.org
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 for the Study of Liver Diseases	http://www.aasld.org/
American Association of Kidney Patients	http://www.aakp.org/
American Association on Intellectual and Developmental Disabilities	http://www.aaid.org
American Autoimmune Related Diseases Association (AARDA)	http://www.aarda.org/
American Autonomic Society	http://americanautonomicsociety.org/
American Behcet's Disease Association	http://www.behcets.com
American Brain Tumor Association	http://www.abta.org
American Cancer Society	http://www.cancer.org
American Childhood Cancer Organization	http://www.acca.org
American Chronic Pain Association (ACPA)	http://www.theacpa.org
American College of Obstetricians and Gynecologists (ACOG)	http://www.acog.org
American Diabetes Association	http://www.diabetes.org
American Dietetic Association	http://www.eatright.org/Public/
American Dystonia Society	http://www.dystonia.us/
American Epilepsy Society	http://www.aesnet.org
American Fibromyalgia Syndrome Association, Inc.	http://www.afsafund.org/
American Foundation for the Blind	http://www.afb.org/
American Gastroenterological Association	http://www.gastro.org/patient
American Hair Loss Association	http://americanhairloss.org

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American Headache Society Committee for Headache Education (ACHE)	http://www.achenet.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 Hemochromatosis Society, Inc.	http://www.americanhs.org
American Institute for Cancer Research	http://www.aicr.org
American Kidney Fund, Inc.	http://www.kidneyfund.org
American Liver Foundation	http://www.liverfoundation.org/
American Lung Association	http://www.lung.org/
American Macular Degeneration Foundation	http://www.macular.org/
American Multiple Endocrine Neoplasia Support	http://www.amensupport.org/
American Orthopaedic Foot & Ankle Society	http://aofas.org/
American Osteopathic College of Dermatology	http://www.aocd.org/
American Parkinson Disease Association	http://www.apdaparkinson.org/
American Partnership For Eosinophilic Disorders	http://www.apfed.org
American Podiatric Medical Association, Inc.	http://www.apma.org/
American Pregnancy Association	http://www.americanpregnancy.org
American RSD Hope Group	http://www.rsdhope.org
American Sickle Cell Anemia Association	http://www.ascaa.org
American SIDS Institute	http://sids.org/
American Skin Association, Inc.	http://www.americanskin.org
American Sleep Apnea Association	http://www.sleepapnea.org
American Sleep Association	http://www.sleepassociation.org/
American Society for Deaf Children (ASDC)	http://www.deafchildren.org/
American Society for Reproductive Medicine	http://www.asrm.org
American Speech-Language-Hearing Association	http://www.asha.org/
American Stroke Association	http://www.strokeassociation.org/
American Syringomyelia Alliance Project, Inc.	http://www.asap.org
American Thyroid Association	http://www.thyroid.org
American Urogynecologic Society	http://www.augs.org/
American Urologic Disease Foundation	http://www.auafoundation.org/
American Uveitis Society	http://www.uveitissociety.org/
American Vitiligo Research Foundation	http://www.avrf.org/index.htm

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Ameriface	http://www.ameriface.org
Amniotic Band Syndrome	http://www.amnioticbandsyndrome.com/
Amputee Coalition of America	http://www.amputee-coalition.org/index.html
Amyloidosis Australia, Inc.	http://www.amyloidosis.com.au/
Amyloidosis Foundation	http://www.amyloidosis.org/
Amyloidosis Support Groups Inc.	http://www.amyloidosissupport.com
Amyotrophic Lateral Sclerosis Association (ALSA)	http://www.alsa.org
Amyotrophic Lateral Sclerosis Society of Canada	http://www.als.ca
ANCA Associated Vasculitis Foundation	http://cureanca.com/
Androgen Insensitivity Syndrome Support Group	http://www.medhelp.org/www/ais
Androgen Insensitivity Syndrome Support Group UK	http://www.aissg.org/
Angelman Syndrome Foundation	http://www.angelman.org/
Angioma Alliance	http://www.angiomaalliance.org
Aniridia Foundation International	http://www.aniridia.net
Annabelle's Challenge	http://www.annabelleschallenge.org
Anorchidism Support Group	http://www.asg4u.org/
Anxiety and Depression Association of America	http://www.adaa.org
Any Baby Can, Inc.	http://anybabycansa.org
AOSupport: Uniting Families Affected by Adams-Oliver Syndrome	http://www.aosupport.org/
APBD Research Foundation	http://www.apbdrf.org
Apert International, Inc.	http://www.apert-international.org
Aphasia Hope Foundation	http://www.aphasiahope.org/
Aplastic Anemia & MDS International Foundation, Inc.	http://www.aamds.org/
Aplastic Anemia and Myelodysplasia	http://www.aamac.ca/index.html
APLASTIC ANEMIA AND OMID'S MISSION FOUNDATION	http://www.aaomf.org
APS Foundation of America, Inc.	http://www.apsfa.org/
Ara Parseghian Medical Research Foundation	http://www.parseghian.org
Arachnoid Cyst Awareness Network	http://arachnoidcystawareness.com/
Arachnoid Cyst Support Group NZ	http://www.arachnoidcyst.org.nz/
Arachnoiditis Sufferers Action and Monitoring Society (ASAMS)	http://www.arachnoiditis.info/index.html
Arc Wisconsin Disability Association, Inc.	http://www.arc-wisconsin.org
ARM (Advancement of Research for Myopathies)	http://www.hibm.org/arm/home

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ARPKD/CHF Alliance	http://www.arpkdchf.org
Arthritis Foundation	http://www.arthritis.org
Arthrogyposis Group	http://tagonline.org.uk
Arthrogyposis Multiplex Congenita Support Inc.	http://www.amcsupport.org
Asherman's Syndrome Int'l Support Group	http://www.ashermans.org
Asociación Colombiana de Esclerosis Lateral Amiotrófica	www.ancelaweb.org
Asociación de Charcot-Marie-Tooth	http://www.cmtausa.org/index.php?option=com_content&view=category&id=55&Itemid=244
Asociación de Síndrome de Ehlers-Danlos e Hiperlaxitud Sede Central	http://asedh.org
Asociación ELA Argentina (ALS Association of Argentina)	www.asociacionela.org.ar/
Asociación Española de ELA	http://www.adelaweb.com/
Asociación Española de Ictiosis	http://ictiosis.org
Asociación Española de Pediatría	http://www.aeped.es
Asociación Española del Síndrome de Beckwith-Wiedemann	http://www.asebewi.org/
Asociación Española para el Estudio de los Errores Congénitos del Metabolismo	http://ae3com.eu/
Asociación Española para la Galactosemia	www.galactosemia.es
Asociación Española Síndrome de Noonan	http://asociacionnoonan.wordpress.com
Asociación Pequeños Gigantes de Colombia	http://www.pequenosgigantesdecolombia.com/
Asociación Piel de Mariposa	http://www.debra.es
Asociación Síndrome de Down de la República Argentina	http://www.asdra.org.ar/que-es-el-sindrome-de-down/
Asociación Síndrome X-Frágil de Madrid	http://www.xfragil.net
Asociación Todos Unidos Enfermedades Raras Uruguay	http://www.enfermedadesrarasuruguay.org.uy/
Asociación X Frágil Colombia	http://www.asociacionxfragilcolombia.org/#!/formulario/c10fe
Asperger Syndrome and High Functioning Autism Association	http://www.ahany.org
Association Européenne contre les Leucodystrophies (ELA)	http://www.ela-asso.com
Association for Children with Down Syndrome, Inc.	http://www.acds.org
Association for Frontotemporal Dementias	http://www.theaftd.org/
Association for Glycogen Storage Disease	http://www.agsdus.org
Association for Glycogen Storage Disease UK	http://www.agsd.org.uk/
Association for Macular Disease, Inc.	http://www.macula.org
Association for Molecular Pathology	http://www.amp.org

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Association for Multiple Endocrine Neoplasia Disorders (AMEND)	http://www.amend.org.uk
Association for Spina Bifida & Hydrocephalus	http://www.asbah.org
Association for the Bladder Exstrophy Community	http://www.bladderexstrophy.com
Association for X and Y Chromosome Variations	http://www.genetic.org
Association of Gastrointestinal Motility Disorders, Inc. (AGMD)	http://www.agmd-gimotility.org
Association of Genetic Support of Australasia, Inc.	http://www.agsa-geneticsupport.org.au/
Association of Peyronie's Disease Advocates	http://www.peyroniesassociation.org/
Association P.A.V.E.L.	http://www.asociatiapavel.ro
Association Paratonnerre	http://www.associationparatonnerre.org/medias/files/newsletter-2-en-web-jan2013.pdf
Associazione Internazionale Ring 14 Per La Ricerca Sulle Malattie Neurogenetiche	http://www.ring14.org
A-T Children's Project	http://www.atcp.org
Ataxia UK	http://www.ataxia.org.uk
Attention Deficit Disorder Resources	http://www.addresources.org
Australasian Genetic Alliance	http://www.australasiangeneticalliance.org.au/
Australasian Society of Clinical Immunology and Allergy	http://www.allergy.org.au/
Australian Arthrogyrosis Group (TAAG), Inc.	http://www.taag.org.au/
Australian Leukodystrophy Support Group	http://www.alds.org.au/
Australian Trimethylaminuria Foundation	http://www.tmaufoundation.org.au
Autism Science Foundation	http://www.autismsciencefoundation.org
Autism Society of America	http://www.autism-society.org
Autism Speaks	http://www.autismspeaks.org
Autoimmune Encephalitis Alliance	https://aealliance.org/
Autoinflammatory Alliance	http://www.nomidalliance.org
AVM Survivors' Network	http://www.avmsurvivors.org/
Baby's First Test	http://www.babysfirsttest.org
Bald Girls Do Lunch Inc	http://www.baldgirlsdolunch.org
Bardet Biedl Syndrome Family Association	http://www.bardetbiedl.org/
Barth Syndrome Foundation	http://www.barthsyndrome.org
Basal Cell Carcinoma Nevus Syndrome Life Support Network	http://www.gorlinsyndrome.org
Batten Disease Support and Research Association (BDSRA)	http://www.bdsra.org/
BCCNS Life Support Network	http://www.bccns.org/

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Beautiful You MRKH Foundation	http://www.beautifulyoumrkh.org/Info.html
Beckwith Wiedemann Support Group (UK)	http://www.bws-support.org.uk/
Beckwith-Wiedemann Children's Foundation	http://www.beckwith-wiedemannsyndrome.org
BEGINNINGS For Parents of Children Who Are Deaf or Hard of Hearing, Inc.	http://www.ncbegin.org
Behcet's Organisation Worldwide	http://www.behcets.org/
Bell's Palsy Network	http://www.bellspalsy.net/
Benign Essential Blepharospasm Canadian Research Foundation	http://www.blepharospasm.ca/
Benign Essential Blepharospasm Research Foundation	http://www.blepharospasm.org
Ben's Friends	http://www.bensfriends.org/
Beyond Batten Disease Foundation	http://www.beyondbatten.org/
BHD Foundation	http://www.bhdsyndrome.org
Biotinidase Deficiency Family Support Group	http://biotinidasedeficiency.20m.com/
Birth Defect Research for Children, Inc.	http://www.birthdefects.org/
Bladder Cancer Advocacy Network	http://www.bcan.org/
Blepharophimosis, Ptosis, Epicanthus Inversus Family Network	http://www.bpes.org.uk
Bloom's Syndrome Association, Inc	http://www.bloomssyndromeassociation.org/
Bloom's Syndrome Foundation	http://www.bloomssyndrome.org/
Blue Faery: the Adrienne Wilson Liver Cancer Association	http://www.bluefaery.org
BOKS vzw	http://www.boks.be
Boomer Esiason Foundation	http://www.esiason.org
Brachial Plexus Palsy Foundation	http://www.brachialplexuspalsyfoundation.org/
Brain Foundation	http://www.brainaustralia.org.au/
Brain Injury Association	http://www.biausa.org
Brain Tumor Foundation for Children, Inc.	http://www.braintumorkids.org
Breast Cancer Network of Strength	http://www.networkofstrength.org
Breast Cancer Options	http://www.breastcanceroptions.org
Breast Friends	http://www.breastfriends.org
Breath of Hope: Congenital Diaphragmatic Hernia (CDH) Awareness	http://www.breathofhopeinc.com
Breathtakers (UK)	http://www.breathtakers.org.uk
Bright Focus Foundation	http://www.brightfocus.org/
Bright Pink	http://www.brightpink.org

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British Association of Dermatologists	http://www.bad.org.uk
Brittle Diabetes Foundation	http://www.bdtype1.com/
Brown-Vialetto-Van Laere International (BVVL International)	http://www.bvvlinternational.org
C3: Colorectal Cancer Coalition	http://www.FightColorectalCancer.org
CADASIL-Together We Have Hope	http://home.earthlink.net/~cadasil/
CAH Support Group	http://www.livingwithcah.com
California Coalition for PKU and Allied Disorders	http://www.ccpkuad.org
Canadian Amyloidosis Support Network	http://thecasn.org/
Canadian Angelman Syndrome Society	http://www.angelmancanada.org
Canadian Association for Williams Syndrome	http://caws.sasktelwebhosting.com/
Canadian Diabetes Association	http://www.diabetes.ca/
Canadian Down Syndrome Society	http://www.cdss.ca
Canadian Fanconi Anemia Research Fund	http://www.fanconicanada.org/en/
Canadian Hemophilia Society	http://www.hemophilia.ca
Canadian Immunodeficiencies Patient Organization (CIPO)	http://cipo.ca
Canadian Marfan Association	http://www.marfan.ca
Canadian Multiple Endocrine Neoplasia Society, Inc.	http://mensociety.ca/
Canadian Organization for Rare Disorders	http://www.raredisorders.ca/
Canadian Pulmonary Fibrosis Foundation	http://www.canadianpulmonaryfibrosis.ca/
Canadian Society for Mucopolysaccharide and Related Diseases Inc. (Canadian MPS Society)	http://www.mpssociety.ca
Canavan Foundation	http://www.canavanfoundation.org
Canavan Research Foundation	http://www.canavan.org
Canavan Research Illinois	http://www.canavanresearch.org
Cancer Hope Network	http://www.cancerhopenetwork.org/
Cancer Information & Support Network	http://cisncancer.org/
Cancer Support Community	http://www.cancersupportcommunity.org/
Cancer.net	http://www.cancer.net/
CancerCare	http://www.cancercare.org/
Cantu Syndrome Interest Group	http://cantu-syndrome.org/
Cardiac Arrhythmias Research and Education Foundation, Inc.	http://www.longqt.org/
Cardiomyopathy Association	http://www.cardiomyopathy.org
Cardiomyopathy Association Australia	http://www.cmaa.org.au/

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Caring for Carcinoid Foundation	http://www.caringforcarcinoid.org/
Caring for the Caregiver	http://caringforthecaregiver.org/
Caring Voice Coalition, Inc,	http://www.caringvoice.org
Carol Ann Foundation & International Morquio Organization	http://www.morquio.com/
Cavernoma Alliance UK	http://www.cavernoma.org.uk
CCARE Lynch Syndrome	http://www.fightlynch.org/
CDG Family Network	http://www.cdgs.com
CDH UK	http://www.cdhuk.co.uk/
CDKL5 Canada	http://www.cdkl5canada.ca/
CDKL5 UK	http://www.cdkl5uk.org
CdLS Foundation	http://www.cdlsusa.org/
CdLS World	http://www.cdlsworld.org
Celiac Sprue Association USA, Inc.	http://www.csaceliacs.org
Center for Jewish Genetics	http://www.jewishgenetics.org
Center for Loss in Multiple Birth	http://www.climb-support.org
Center for Parent Information and Resources	http://www.parentcenterhub.org/
Centers for Vulvovaginal Disorders	http://www.cvvd.org/
Cerebral Palsy International Research Foundation	http://www.cpirf.org
Cerebral Palsy Network	http://thecpnetwork.org/megalencephaly.html
CFC International	http://cfcsyndrome.org/
CFIDS Association of America, Inc.	http://www.cfids.org
CGD Society	http://www.cgdsociety.org
CHADD (Children & Adults with Attention-Deficit Hyperactivity Disorder)	http://www.chadd.org
Chagas Disease Foundation	http://www.chagasfound.org/
Charcot-Marie-Tooth Association	http://www.charcot-marie-tooth.org/
Charcot-Marie-Tooth Association of Australia	http://www.cmt.org.au/
CHARGE Syndrome Foundation	http://www.chargesyndrome.org
Charles E. Holman Foundation	http://www.thecehf.org/
Charley's Fund, Inc.	http://www.charleysfund.org
CHASER (Congenital Heart Anomalies -- Support, Education & Resources, Inc.)	http://www.csun.edu/~hcmth011/chaser/contact.html
Chelsea's Hope: Lafora Children Research Fund	http://www.chelseashope.org/
Cherab Foundation	http://www.cherabfoundation.org

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CHERUBS	http://www.cherubs-cdh.org
Chiari & Syringomyelia Foundation, Inc.	http://www.csfinfo.org/
Chicago Center for Jewish Genetic Disorders	http://www.jewishgeneticscenter.org
Childhood Apraxia of Speech Association of North America (CASANA)	http://www.apraxia-kids.org
Children Living with Inherited Metabolic Diseases (CLIMB)	http://www.climb.org.uk
Children with Spinal Muscular Atrophy	http://www.csma.org.ua
Children's Liver Association for Support Services	http://www.classkids.org
Children's Neurobiological Solutions Foundation	http://cnsfoundation.org/
Children's PKU Network	http://www.pkunetwork.org/
Children's Alopecia Project, Inc.	http://www.childrenalopeciaproject.org
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.childrencbf.org
Children's Cardiomyopathy Foundation	http://www.childrencardiomyopathy.org/
Children's Craniofacial Association	http://www.ccakids.com/
Children's Digestive Health & Nutrition Foundation	http://www.cdhnf.org/
Children's European Mitochondrial Disease Network	http://www.emdn-mitonet.co.uk
Children's Fund for Glycogen Storage Disease Research, Inc.	http://www.cureGSD.org
Children's Gaucher Research Fund	http://www.childrengaucher.org
Children's Glaucoma Foundation	http://www.childrenglaucoma.com
Children's Interstitial Lung Disease (ChILD) Foundation	http://www.child-foundation.com
Children's Liver Association for Support Services (C.L.A.S.S.)	http://www.classkids.org/
Children's Liver Disease Foundation	http://www.childliverdisease.org/
Children's Neuroblastoma Cancer Foundation	http://www.cncfhope.org/
Children's Sickle Cell Foundation, Inc.	http://www.cscfkids.org
Children's Skin Disease Foundation	https://www.csdf.org/
Chordoma Foundation	http://www.chordomafoundation.org/
Chordoma Support Group	http://www.chordomasupport.org
Choroideremia Research Foundation Canada, Inc.	http://www.choroideremia.ca/
Choroideremia Research Foundation, Inc.	http://choroideremia.org/
Christopher and Dana Reeve Foundation	http://www.christopherreeve.org
Chromosome 18 Registry & Research Society	http://www.chromosome18.org/

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Chromosome 22 Central - Latinoamérica	http://www.c22c.org
Chromosome 22 Central - Main Office	http://www.c22c.org/
Chromosome 22 Central - US Office	http://www.c22c.org
Chromosome 9 Disorder Advocates	http://chromosome9.org
Chromosome 9pminus Network	http://www.9pminus.org
Chromosome Disorder Outreach	http://www.chromodisorder.org
Chronic Fatigue and Immune Dysfunction Syndrome Association of America, Inc.	http://www.cfids.org
Chronic Granulomatous Disease Association, Inc.	http://www.cgdassociation.org/
Chronic Granulomatous Disorder Research Trust (CGD)	http://www.cgd.org.uk/
Chronic Granulomatous Disorder Society	http://www.cgdsociety.org/
Chronic Lymphocytic Leukemia Information Group	http://www.cllinfogroup.org
Churg Strauss Syndrome Association	http://www.cssassociation.org
Cicatrical Alopecia Research Foundation (C.A.R.F.)	http://www.carfintl.org
CIDPUSA Foundation	http://www.cidpusa.org
Cincinnati Center for Eosinophilic Disorders	http://www.cincinnatichildrens.org/service/c/eosinophilic-disorders/default/
Cincinnati Children's Hospital - HLH	http://www.cincinnatichildrens.org/service/h/hlh/about/
Circadian Sleep Disorders Network	http://www.circadiansleepdisorders.org/
Citizens for Quality Sickle Cell Care-SCDAA-Northern, CT Chapter, Inc.	http://www.cqsc.org
Citizens United for Research in Epilepsy	http://www.CUREepilepsy.org
CJD Aware!	http://www.cjdaware.com
CJD Voice	http://creativegumbo.net/cjdvoice/
Claire Altman Heine Foundation, Inc.	http://www.preventsma.org
Cleft Palate Foundation	http://www.cleftline.org/
ClinicalTrials.gov	http://www.clinicaltrials.gov/ct2/results?cond=%22Acanthocheilonemiasis%22
Clot Connect	http://www.clotconnect.org/
CLOVES Syndrome Community	http://www.clovessyndrome.org/
CLOVES Syndrome Foundation	http://clovesfoundation.org/
C-Mac Informational Services/Caregiver News [For Alzheimer's-Type Dementia Caregivers]	http://www.caregivernews.org
CMT United Kingdom	http://www.cmt.org.uk
CMTC	http://www.cmtc.nl
CMTC-OVM	http://cmtc.nl/index.php?lang=en&Itemid=105

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Coalition Duchenne	http://www.coalitionduchenne.org
Coalition for Heritable Disorders of Connective Tissue	http://www.chdct2.org/index.htm
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
Coffin-Lowry Syndrome Foundation	http://clsf.info/
Cohen Syndrome Association	http://cohen-syndrome.org/
Collaborative Group of the Americas in Inherited Colorectal Cancer (CGA)	http://www.cgaicc.com
Colon Cancer Alliance	http://www.ccalliance.org
Colorectal Cancer Association of Canada	http://www.colorectal-cancer.ca
Compassionate Friends	http://www.compassionatefriends.org
Congenital Adrenal Hyperplasia Education and Support Network	http://www.congenitaladrenalhyperplasia.org
Congenital Adrenal Hyperplasia Research Education and Support (CARES) Foundation	http://www.caresfoundation.org
Congenital Adrenal Hyperplasia Support Group of NZ or CAHNZ Trust	http://www.cah.org.nz/
Congenital Central Hypoventilation Syndrome (CCHS) Family Support Network	http://www.cchsnetwork.org/
Congenital Heart Anomalies, Support, Education, & Resources, Inc. (CHASER, Inc.)	http://www.csun.edu/~hcmth011/chaser/chaser-news.html
Congenital Heart Information Network	http://tchin.org/
Congenital Heart Information Network (C.H.I.N.)	http://www.tchin.org
Congenital Hyperinsulinism International	http://www.congenitalhi.org/
Congenital Sucrase-Isomaltase Deficiency (CSID) Parent Support Group	http://www.csidinfo.com
Conquer Chiari	http://www.conquerchiari.org/index.html
Conversations!	http://www.ovarian-news.org
Cooley's Anemia Foundation	http://www.cooleysanemia.org
COPD Foundation	http://www.copdfoundation.org
CORE	http://www.corecharity.org.uk
Cornea Research Foundation of America	http://www.cornea.org
Corneal Dystrophy Foundation	http://www.cornealdystrophyfoundation.org
Cornelia de Lange Syndrome Foundation, Inc.	http://www.cdlsusa.org
Corpus Callosum Research Program	http://emotion.caltech.edu/agcc/index.html
Cortical Foundation	http://cortfoundation.org/

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Costello Syndrome Family Network	http://www.costellosyndromeusa.org/
Craniofacial Foundation of America	http://www.craniofacialfoundation.org
Craniosynostosis and Positional Plagiocephaly Support Inc	http://www.cappskids.org
Creutzfeldt-Jakob Disease Foundation, Inc	http://www.cjdfoundation.org/
Crigler-Najjar Association	http://www.criglenajjar.com
Crohn's & Colitis Foundation of America	http://www.cffa.org
CSID Cares	http://csidcares.org/
Cure CMD - Congenital Muscular Dystrophy	http://curecmd.org/
Cure Dystonia Now	http://www.curedystonianow.org/index
Cure HHT	http://curehht.org/
Cure SMA	http://www.curesma.org
CURED Foundation	http://curedfoundation.org/site/
CureDuchenne	http://www.cureduchenne.org
CurePSP (Society for Progressive Supranuclear Palsy)	http://www.psp.org/
Cushing's Support and Research Foundation	http://csrf.net
Cutaneous Lymphoma Foundation	http://www.clfoundation.org/
Cutis Laxa Internationale	http://asso.orpha.net/cutislax/
Cyclic Vomiting Syndrome Association	http://www.cvsaonline.org
Cystic Fibrosis Foundation	http://www.cff.org
Cystic Fibrosis Research, Inc.	http://www.cfri.org
Cystinosis Foundation	http://www.cystinosisfoundation.org/
Cystinosis Research Foundation	http://www.cystinosisresearch.org
Cystinosis Research Network	http://www.cystinosis.org/
Cystinuria Support Network	http://www.cystinuria.com/
Dancing Eye Syndrome Support Trust	http://www.dancingeyes.org.uk
Dandy-Walker Alliance, Inc.	http://www.dandy-walker.org
Daniella Maria Arturi Foundation	http://diamondblackfanemia.org
Danon Disease Support Network	http://danon-disease-support.webs.com/
DanonDisease.org	http://www.danondisease.org/
DebRA Chile	http://debrachile.cl
debra Costa Rica	http://www.debracr.org
DebRA International	http://www.debra-international.org/
Depression and Bipolar Support Alliance	http://www.dbsalliance.org

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Desmoid Tumor Research Foundation	http://www.dtrf.org/
Deutsches Register Morbus Adamantiades-Behçet eV	http://www.behcet.de
Developmental Delay Resources	http://www.devdelay.org/
Developmental Delay Resources (DDR)	http://www.devdelay.org
Devic's Disease UK	http://www.devic.org.uk/
Diabetes Action Research and Education Foundation	http://www.diabetesaction.org
Diabetes Hands Foundation	http://www.diabeteshandsfoundation.org
Diabetes New Zealand	http://www.diabetes.org.nz/
Diamond Blackfan Anemia and You	http://www.diamondblackfananemia.com/
Diamond Blackfan Anemia Foundation, Inc.	http://www.dbafoundation.org/
Disorders of Chromosome 16 Foundation	http://www.trisomy16.org/
DNAandU.org	http://www.dnaandu.org/
Doose Syndrome Epilepsy Alliance	http://www.doosesyndrome.org/
Down España	http://www.sindromedown.net/
Down Syndrome Alabama	http://www.downsyndromealabama.org
Down Syndrome Association of Acadiana	http://www.dsaa.info
Down Syndrome Association of Atlanta	http://www.dsaatl.org
Down Syndrome Association of Greater St. Louis	http://www.dsagsl.org
Down Syndrome Information Alliance	http://downsyndromeinfo.org/
Down Syndrome Research and Treatment Foundation	http://www.dsrtf.org/
Down Syndrome: Health Issues	http://www.ds-health.com/
Dr. Susan Love Research Foundation	http://www.dslrf.org
Dravet Syndrome Foundation	http://www.dravetfoundation.org/
Dravet.org	http://dravet.org/
Dubowitz Syndrome Family Support	http://www.dubowitzsyndrome.net
Dubowitz Syndrome Family Support Network	http://www.ric.edu/sherlockcenter/dsyndrome/
Duchenne Connect	https://www.duchenneconnect.org
Dup15q Alliance	http://www.dup15q.org/
Dysautonomia Foundation, Inc	http://www.familialdysautonomia.org/
Dysautonomia International	http://www.dysautonomiainternational.org/
Dysautonomia Support Network	http://www.supportdysautonomia.org/
Dysautonomia Youth Network of America	http://www.dynainc.org/
Dystonia Medical Research Foundation	http://www.dystonia-foundation.org

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Dystrophic Epidermolysis Bullosa Research Association	http://www.debra.org
Dystrophic Epidermolysis Bullosa Research Association of America	http://www.debra.org/espanol
EB Medical Research Foundation	http://www.ebkids.org/
Ebstein's Anomaly Foundation	http://www.ebsteinsanomaly.org/
ECD Global Alliance	http://www.erdheim-chester.org
EDS Today	http://www.edstoday.org
Ehlers Danlos Foundation of New Zealand	http://www.edfnz.org.nz
Ehlers Danlos National Foundation	http://www.ednf.org
Ehlers-Danlos Support UK	http://www.ehlers-danlos.org
Ehlers-Danlos Syndrome Network	http://www.ehlersdanlosnetwork.org
El Instituto Nacional de Artritis y Enfermedades Musculoesqueléticas y de la Piel (NIAMS)	http://www.niams.nih.gov
Ellie White Foundation	http://elliewhitefoundation.org/
Emmanuel's Foundation	http://www.EmmanuelFoundation.org
Encephalitis Global Inc.	http://www.encephalitisglobal.org
Encephalitis Ireland	http://www.encephalitisireland.ie/
Encephalitis Society	http://www.encephalitis.info/
Endometriosis Association	http://www.endometriosisassn.org
Energy 4 a Cure Foundation	http://www.rvclresearch.org/index.php
Ependy Parents	http://ependyparents.org/
EpendyKids	http://ependykids.com/
Epidermolysis Bullosa (EB) Center	http://www.cincinnatichildrens.org/svc/alpha/e/epidermolysis-bullosa/
Epidermolysis Bullosa Medical Research Foundation	http://www.ebkids.org
Epilepsy Action	https://www.epilepsy.org.uk/
Epilepsy Foundation	http://www.epilepsyfoundation.org/
Epilepsy Support Network of Orange County	http://www.EpilepsySupportNet.org
Erfocentrum	http://www.erfocentrum.nl/new
Erythromelalgia Association	http://www.erythromelalgia.org
Esophageal Cancer Awareness Association, Inc.	http://www.ECAware.org
Euro-Ataxia (European Federation of Hereditary Ataxias)	http://www.euro-ataxia.eu/
EuroGentest	http://www.eurogentest.org/
EuroMX Consortium Registry	http://www.euomrx.com/

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European Alliance of Neuromuscular Disorders Associations	http://www.eamda.net
European Chromosome 11 Network	http://11q.chromosome11.eu/
European Federation of Autonomic Nervous System Societies	http://www.efasweb.com/efas/
European LAM Patient Federation	http://www.europelamfederation.org/
European Network for Rare and Congenital Anaemias (ENERCA)	http://www.enerca.org
European Skeletal Dysplasia Network	http://www.esdn.org/eug/Home
EURORDIS Plateforme Maladies Rares	http://www.eurordis.org
Evanosky Foundation	http://www.evanoskyfoundation.org
Evans Syndrome Community Network	http://www.evanssyndrome.net/
EveryLife Foundation for Rare Diseases	http://www.everylifefoundation.org/
everyminute.org	http://www.everyminute.org
Eye on Vision Foundation	http://eyeonvision.org/
Fabry Support & Information Group	http://www.fabry.org
FACES: The National Craniofacial Association	http://www.faces-cranio.org/
Facial Paralysis Foundation	http://www.facialparalysisfoundation.org/
Familial Dysautonomia Hope Foundation	http://www.fdhope.org
Familial Dysautonomia Now Foundation (FD NOW)	http://www.fdnw.org
Familias de la Atrofia Muscular Espinal	http://www.fsma.org/FSMACommunity/understandingsma/spanishunderstandingbook/
Families of SMA	http://www.fsma.org/
Families of Spinal Muscular Atrophy Canada	http://www.curesma.ca/
Family Caregiver Alliance/ National Center on Caregiving	http://www.caregiver.org
Family Connect	http://www.familyconnect.org/
Family Connect: for parents of children with visual impairments	http://www.familyconnect.org/parentsitehome.asp
Family Empowerment Network	http://www.pregnancyandalcohol.org
Family Resource Center on Disabilities	http://www.frcd.org
Family Support Network	http://www.familysupportnetwork.org/
Family Voices in Oklahoma	http://OKVoices.org
Family Voices of California	http://www.familyvoicesofca.org
Fanconi Anemia Research Fund, Inc (FARF)	http://www.fanconi.org
Fat Disorders Research Society	http://www.fatdisorders.org

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Federación Argentina de Enfermedades Poco Frecuentes	http://fadepof.org.ar/contacto
Federación Colombiana de Enfermedades Raras	http://www.fecoer.org
Federación Española de Enfermedades Metabólicas Hereditarias	http://www.metabolicos.es/
Federación Española de las Asociaciones de Linfedema	http://www.feddeal.org/
Federación Española de las Enfermedades Neuromusculares	http://www.asem-esp.org
Federación Española del Síndrome X Frágil	http://www.xfragil.org/
Federación Peruana de Enfermedades Raras	http://fepepc.blogspot.com/
Fetal Hope Foundation	http://www.fetalhope.org
FEVR.net	http://www.fevr.net/
FG Syndrome Family Alliance	http://www.fgsyndrome.org/
Fibrolamellar Cancer Foundation	http://www.fibrofoundation.org/
Fibromyalgia Association UK	http://www.fmauk.org
Fibromyalgia Network	http://www.fmnetnews.com
Fibrosing Mediastinitis	http://www.fibrosing-mediastinitis.com/
Fibrous Dysplasia Foundation, Inc.	http://www.fibrousdysplasia.org
Fight ALD	http://www.fightald.org
FightSMA/Andrew's Buddies	http://www.fightsma.org
First Candle/SIDS Alliance	http://www.firstcandle.org
Floating Harbor Syndrome Support Group	http://www.floatingharborsyndromesupport.com/
FMD Chat	http://www.fmdchat.org
FMF Montreal.org	http://www.fmfmontreal.org/
FND Hope	http://fndhope.org/
FOCUS Families	http://www.focusfamilies.org
Focus On Chronic Lymphocytic Leukemia	http://www.focusoncll.org
FOD (Fatty Oxidation Disorder) Family Support Group	http://www.fodsupport.org
FORCE: Facing Our Risk of Cancer Empowered	http://www.facingourrisk.org
Foundation Fighting Blindness	http://www.blindness.org
Foundation for Angelman Syndrome Therapeutics	http://www.cureangelman.org/
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 Nager and Miller Syndromes	http://www.fnms.net

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Foundation for Prader-Willi Research	http://www.fpwr.org/
Foundation for Retinal Research	http://www.tfrr.org/
Foundation for Sarcoidosis Research	http://www.stopsarcoidosis.org
Foundation to Eradicate Duchenne	http://www.duchennemd.org
FRAXA Research Foundation	http://www.fraxa.org
Freeman-Sheldon Parent Support Group	http://www.fspsg.org
Freeman-Sheldon Research Group, Inc.	http://www.fsrgroups.org/
Friedreich's Ataxia Parents' Group	http://www.faparents.org/fapg/
Friedreich's Ataxia Research Alliance (FARA)	http://www.curefa.org/
Friends of Autism, Inc.	http://www.friendsofautism.org
Friends of ET Research	http://www.friendsofetresearch.org
Friends of FSH Research	http://www.fshfriends.org/
Friends of Landau-Kleffner Syndrome (FOLKS)	http://www.friendsoflks.com
Frontotemporal Dementia Caregiver Support Center	http://www.ftdsupport.com
Frontotemporal Lobar Degeneration Association (FTLDA)	http://www.ftlda.org/
FSH Society, Inc.	http://www.fshsociety.org
FSHD Global Research Foundation	http://www.fshdglobal.org/
Fundació Catalana Síndrome de Down	http://www.fcsd.org/es
Fundación ACAR	http://acondroplasia.jimdo.com
Fundación ALPE	http://www.fundacionalpe.org/
Fundación Angiopediatria Colombia	http://angiopediatria.com.co/
Fundación Atrofia Muscular Espinal	http://www.fundame.net
Fundación Cromos	http://www.fundacioncromos.org
Fundación Geiser	http://www.fundaciongeiser.org/
Fundación Magar	http://www.acondroplasia.com/index2.php
Fundación Para la Investigación de la Esclerosis Lateral Amiotrófica	http://www.fundacionela.com
FVL Thrombophilia Support Page	http://www.fvleiden.org/
Galactosemia Foundation	http://www.galactosemia.org
Galactosemia Support Group	http://www.galactosaemia.org/
Gastroparesis and Dysmotilities Association (GPDA)	http://www.digestivedistress.com/main/page.php?page_id=1
Gastroschisis Exomphalos Extrophies Parents Support	http://www.geeps.co.uk/
GBS/CIDP Foundation International	http://www.gbs-cidp.org
Genetic Alliance	http://www.geneticalliance.org/

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Genetic Interest Group	http://www.gig.org.uk
Genetic Metabolic Dietitians International	http://www.gmdi.org/
Genetic Skin Disease Center	http://dermatology.stanford.edu/contact/
Genetic Support Network of Victoria	http://www.gsnv.org.au
Genetics Home Reference (GHR)	http://ghr.nlm.nih.gov/condition=abetalipoproteinemia
Georgia PKU Connect	http://www.georgiapku.org
Getty Owl Foundation	http://www.gettyowl.org
GiGi's Playhouse	http://gigisplayhouse.org/
GIST Cancer Research Fund	http://www.gistinfo.org/
GIST Support International	http://www.gistsupport.org
Glaucoma Research Foundation	http://www.glaucoma.org
Glaucoma Research Society of Canada	http://www.glaucomaresearch.ca/
Global CDH	http://globalcdh.org/Home.html
Global Foundation for Peroxisomal Disorders	http://www.thegfpd.org
Global Genes - Allies in Rare Disease	http://globalgenes.org/
Global Hydranencephaly Foundation	http://www.hydranencephalyfoundation.org/
Global Organization for Lysosomal Diseases	http://www.goldinfo.org/
Glut1 Deficiency Foundation	http://www.G1DFoundation.org
Gluten Intolerance Group	http://www.gluten.net
Goldenhar Syndrome Support Network Society	http://www.goldenharsyndrome.org
Graves' Disease and Thyroid Foundation	http://www.gdatf.org/
Graves' Disease Foundation	http://www.ngdf.org
Greenberg Center for Skeletal Dysplasias	https://igm.jhmi.edu/content/greenberg-center-skeletal-dysplasias-welcome
Greipp, Philip R, M.D.	http://www.mayoclinic.org/bio/10157425.html
Grupo Español de Pacientes con Cáncer	http://www.gepac.es/
Guthy-Jackson Charitable Foundation	http://www.guthyjacksonfoundation.org/
Gwendolyn Strong Foundation	http://theGSF.org
Haemochromatosis Australia.	http://www.haemochromatosis.org.au
Hailey-Hailey Disease Society	http://haileyhailey.com
Hailey's Wish	http://www.haileyswish.org/
Hajdu-Chaney (HCS) Support Group	http://www.hajdu-cheney.com/
Hands & Voices	http://www.handsandvoices.org
Hannahs Hope Fund	http://www.hannahshopefund.org/

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Hashimoto's Encephalopathy SREAT Alliance	http://hesaonline.org/
HCS Support Group	http://hajdu-cheney.com/
Healthy Smiles, Healthy Children	http://www.aapd.org/foundation/
Hearing Loss Association of America	http://www.hearingloss.org
Heart Rhythm Society	http://www.hrsonline.org/
Helping After Neonatal Death (HAND)	http://www.handonline.org/resources/handgroups.html
Helping Hands Foundation	http://www.helpinghandsgroup.org/
Hemimegalencephaly Family Support Network	http://www.hemimegalencephaly.com/
Hemophilia Federation of America	http://hemophiliafed.org/
Hepatitis Foundation International	http://www.hepatitisfoundation.org
Hereditary Disease Foundation	http://www.hdfoundation.org
Hereditary Leiomyomatosis and Renal Cell Cancer (HLRCC) Family Alliance	http://www.hlrccinfo.org/
Hereditary Neuropathy Foundation Inc.	http://www.hnf-cure.org/
Hermansky-Pudlak Syndrome Network, Inc.	http://www.hpsnetwork.org/en
Heterotaxy Foundation	http://www.heterotaxy.org/
HHV-6 Foundation	http://www.hhv-6foundation.org
Hide and Seek Foundation for Lysosomal Storage Disease Research	http://www.hideandseek.org
Hidradenitis Suppurativa Foundation, Inc.	http://www.hs-foundation.org/
Hirschsprung's & Motility Disorders Support Network	http://www.hirschsprungs.info
Histiocytoid Cardiomyopathy Registry	http://www.pathology.emory.edu/AdminFacultyMember.cfm?Name_seq=709
Histiocytosis Association of America	http://www.histio.org/
Histiocytosis Association of Canada	http://www.histiocytosis.ca
HITS (Worldwide) Family Support Network	http://www.e-fervour.com/hits/
Hope 4 Tyler and Luke!	http://www.hope4tylerandluke.com
Hope for Hypothalamic Hamartomas	http://hopeforhh.org/
Hope For Trisomy	http://www.hopefortrisomy.org
Hope for Two...The Pregnant with Cancer Network	http://www.hopefortwo.org
HOPES	http://hopes.stanford.edu
Human Growth Foundation	http://www.hgfound.org/
Hunter Patients	http://www.hunterpatients.com/
Hunter's Hope Foundation	http://www.huntershope.org
Huntington Society of Canada	http://www.huntingtonsociety.org/

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Huntington's Disease Society of America	http://www.hdsa.org/
Hydrocephalus Association	http://www.hydroassoc.org
Hydrocephalus Research Foundation	http://www.ghrforg.org/
Hypertrophic Cardiomyopathy Association	http://www.4hcm.org
Hypoparathyroidism Association, Inc.	http://www.hpth.org/
Hypoparathyroidism UK	http://www.hpth.org.uk
Hypophysitis Research Center	http://pathology2.jhu.edu/hypophysitis/Definition.cfm
Hypospadias Epispadias Association	http://www.HEAinfo.org
I - CAN	http://child-amputee.net/
Ichthyosis Support Group	http://www.ichthyosis.org.uk/
ICP Care	http://www.icpcare.org
ICP Support	http://www.icpsupport.org/
IDIC15 Canada	http://www.idic15canada.ca/
IgA Nephropathy Support Network	http://www.igansupport.org/
Immune Deficiencies Foundation Australia	http://www.idfa.org.au/
Immune Deficiency Foundation	http://www.primaryimmune.org/
In Need of Diagnosis, Inc.	http://www.inod.org/home0.aspx
Incontinentia Pigmenti International Foundation	http://www.ipif.org/
India Cancer Care Network (ICCN)	http://www.iccn.in/
Infectious Diseases Society of America	http://www.idsociety.org/
Inflammatory Breast Cancer Foundation	http://www.eraseibc.com/
Instituto Canguru - Support Group for Inborn Errors of Metabolism and Disorders	http://www.institutocanguru.org.br
Instituto Nacional del Cáncer (NCI)	http://www.cancer.gov/espanol
Intermountain PKU and Allied Disorders Association	http://www.go-ipad.org
International Aicardi-Goutieres Syndrome Association (IAGSA)	http://www.aicardi-goutieres.org/index.jsp?lingua=ENG
International Alliance of Patients' Organizations	http://www.patientsorganizations.org/
International Birth Defects Information Systems	http://www.ibis-birthdefects.org/start/found.htm
International Brain Tumour Alliance	http://www.theibta.org/
International Castleman's Disease Organization	http://www.castlemans.org/about
International Children's Anophthalmia Network (ICAN)	http://www.anophthalmia.org
International Cluttering Association	http://associations.missouristate.edu/ica/
International Collaborative Study of Susac's Syndrome	http://www.ucalgary.ca/susac/clinicalstudyall
International Costello Syndrome Support Group	http://costellokids.com/

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International Costello Syndrome Support Group	http://www.costellokids.com
International Cystinuria Foundation	http://www.cystinuria.org/resources/education/
International Diabetes Federation (IDF)	http://www.idf.org/
International Dyslexia Association	http://www.interdys.org
International Eosinophil Society	http://www.eosinophil-society.org/
International Essential Tremor Foundation	http://www.essentialtremor.org
International Federation of Anti-Leprosy Associations (ILEP)	http://www.ilep.org.uk
International Fibrodysplasia Ossificans Progressiva Association	http://www.ifopa.org/
International Foundation for CDKL5 Research	http://www.cdkl5.com
International Foundation for Functional Gastrointestinal Disorders	http://www.iffgd.org/
International Foundation for Optic Nerve Disease (IFOND)	http://www.ifond.org
International Foundation of Marfan Syndrome Organizations	http://www.marfanworld.org
International FoxG1 Foundation	http://www.foxg1.com/
International Glaucoma Association	http://www.iga.org.uk
International Hip Dysplasia Institute	http://www.hipdysplasia.org/
International Huntington Association	http://www.huntington-disease.org
International Hyperhidrosis Society	http://www.SweatHelp.org
International Lyme and Associated Diseases Society	http://ilads.org/
International Mosaic Down Syndrome Association	http://www.imdsa.org
International Mosaic Down Syndrome Association	http://www.imdsa.org/Espanol
International Myeloma Foundation	http://myeloma.org/
International Myotonic Dystrophy Family Foundation	http://www.myotonic.org/
International Myotonic Dystrophy Organization	http://www.myotonicdystrophy.org
International OCD Foundation	http://www.ocfoundation.org
International Organization of Glutaric Aciduria	http://www.glutaricacidemia.org/
International Osteoporosis Foundation	http://www.iofbonehealth.org/
International Palindromic Rheumatism Society	http://www.palindromicrheumatism.org/
International Patient Organization for Patients with Primary Immunodeficiencies	http://www.ipopi.org/
International Pediatric Hypertension Association	http://www.pediatrichypertension.org
International Pemphigus & Pemphigoid Foundation	http://www.pemphigus.org
International Prader-Willi Syndrome Organisation	http://www.ipwso.org

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International Premature Ovarian Failure Association	http://www.ipofa.org/
International RadioSurgery Association	http://www.irsas.org
International Rett Syndrome Association	http://www.rettysyndrome.org/
International Scleroderma Network (ISN)	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 WAGR Syndrome Association	http://www.wagr.org
International Waldenstrom's Macroglobulinemia Foundation	http://www.iwfm.com/
Intersex Society of North America (ISNA)	http://www.isna.org/
Interstitial Cystitis Association	http://www.ichelp.org
Intracranial Hypertension Research Foundation	http://www.ihrfoundation.org
Intractable Childhood Epilepsy Alliance	http://www.ice-epilepsy.org/
Iowa Federation of Families for Children's Mental Health	http://www.iffcmh.org
Iron Disorders Institute Inc.	http://www.irondisorders.org/
Iron Overload Diseases Association, Inc.	http://www.ironoverload.org
Italian Registry of MYH9-Related Disease	http://www.registromyh9.org/
ITP Foundation	http://www.itpfoundation.org
It's My Heart, Inc.	http://www.itsmyheart.org
Jacob's Cure	http://www.jacobscure.org
Jain Foundation	https://www.jain-foundation.org/
Janine's sarcoidosis outreach foundation	http://www.jsf.org
JDRF Monogenic Diabetes Section	http://www.monogenicdiabetes.org/index.html
Jeffrey Modell Foundation/National Primary Immunodeficiency Resource Center	http://www.info4pi.org/
Jeunes Syndrome Family Foundation	http://www.jeunesfamily.org/
Jewish Genetic Disease Consortium (JGDC)	http://www.JewishGeneticDiseases.org
JMML Foundation, The	http://www.jmmlfoundation.org
John Douglas French Alzheimer's Foundation	http://www.jdfaf.org
Jonah's Just Begun-Foundation to Cure Sanfilippo Inc.	http://jonahsjustbegun.org/
Joshua Frase Foundation	http://www.joshuafrase.org
Joubert Syndrome & Related Disorders Foundation	http://www.joubertfoundation.com/
Joubert Syndrome and Related Disorders Foundation	http://www.jsrdf.org

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Justin E. Rodgers Foundation for Lemierre's Awareness, Inc.	http://www.lemierresyndrome.com/
Juvenile Diabetes Research Foundation International	http://www.jdrf.org/
Juvenile Scleroderma Network	http://www.jsdn.org
Kabuki Syndrome Network	http://kabukisyndrome.com/
Kartagener's Syndrome and Primary Ciliary Dyskinesia Foundation	http://www.kartagener-syndrom.org/cms/index.php?lang=en
Kawasaki Disease Foundation	http://www.kdfoundation.org/
Kawasaki Support Group	http://www.kssg.org.uk
Kennedy's Disease Association	http://www.kennedysdisease.org
KFS Circle of Friends:	https://sites.google.com/site/kfscircle/
KickAS.org	http://www.kickas.org
Kidney Cancer Association	http://KidneyCancer.org
Kids v Cancer	http://www.kidsvcancer.org/
Kids With Food Allergies Foundation	http://www.kidswithfoodallergies.org
Kids with Heart National Association for Children's Heart Disorders	http://www.kidswithheart.org
Kleefstrasynndrome.org	http://www.kleefstrasynndrome.org/
Kleine Levin Syndrome Foundation	http://www.klsfoundation.org
Klippel-Feil Syndrome Alliance	http://kfsalliance.org/
Klippel-Trenaunay Support Group	http://k-t.org/
Kniest SED Group	http://www.ksginfo.org/kniest.html
Kommah Seray Inflammatory Breast Cancer Foundation	http://www.ksibcf.org
Kure It	http://www.kureit.org
La Asociación de Afectados de Neurofibromatosis	http://www.neurofibromatosis.es
La Federación Española de Enfermedades Raras (FEDER)	http://www.enfermedades-raras.org
La Federación Mexicana de Enfermedades Raras (FEMEXER)	http://www.femexer.org/
La Leche League International	http://www.llli.org
La Sociedad Americana Contra el Cancer	http://www.cancer.org/espanol/
LAM Action	http://lamaction.org/
LAM Treatment Alliance	http://www.curelam.org
Laryngeal Cleft	http://www.laryngeal-cleft.com
Laryngeal Cleft European Support Group	http://laryngeal-cleft-support-group.ning.com/
Laryngeal Cleft Kids	http://laryngealcleftkids.ning.com/

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Late Onset Tay-Sachs Research and Education Foundation	http://www.lateonsettay-sachs.org/
Laurence-Moon Bardet-Biedl Society UK	http://www.lmbbs.org.uk/
Laurence-Moon-Bardet-Biedl Society (LMBBS)	http://www.lmbbs.org.uk
LDNZ (Lysosomal Diseases New Zealand)	http://www.ldnz.org.nz/
Learning Disabilities Association of America	http://www.laamerica.org
Leber's Hereditary Optic Neuropathy Website	http://www.lhon.org
Les Turner ALS Foundation	http://www.lesturnerals.org/
Lesch Nyhan.org and Lesch Nyhan International Study Group	http://www.lesch-nyhan.org/en/research/
Lesch-Nyhan Disease International Study Group	http://www.lesch-nyhan.org
Let's Face It	http://desica.dent.umich.edu/faceit/
Leukemia Foundation	http://www.leukaemia.org.au/
Lewy Body Dementia Association	http://www.lbda.org/
LGS Foundation	http://lgsfoundation.org/index.html
Liam's Land Organization, Inc.	http://www.liamsland.org/
Li-Fraumeni Syndrome Association	http://www.lfsassociation.org/
Lighthouse International	http://www.lighthouse.org
Limb Differences	http://limbdifferences.org/
Lissencephaly Contact Group	http://www.lissencephaly.org.uk
Little People of America	http://www.lpaonline.org/informacin-en-espaol
Little People of America, Inc.	http://www.lpaonline.org/
Littlest Tumor Foundation	http://www.littlesttumor.org
LIVESTRONG.- Lance Armstrong Foundation	http://www.livestrong.org/
Living Beyond Breast Cancer	http://www.lbbc.org
Living with CIDP	http://www.livingwithcidp.org/
Living With Trisomy 13	http://www.livingwithtri13.org
LivingWithEagle.org	http://www.livingwitheagle.org/
LMSarcoma Direct Research Foundation	http://www.lmsdr.org
Locks of Love	http://www.locksoflove.org/
Loeys-Dietz Syndrome Foundation - Canada	http://www.loeys-dietzsyndromecanada.org
Loeys-Dietz Syndrome Foundation (US)	http://www.loeysdietz.org/
Lowe Syndrome Association	http://www.lowesyndrome.org/
LPLD Connect	http://www.lpldconnect.org
Lung Cancer Alliance	http://www.lungcanceralliance.org

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Lupus Foundation of America	http://www.lupus.org/
Lymphangiomatosis & Gorham's Disease Alliance	http://www.lgdalliance.org/
Lymphatic Education and Research Network	http://www.lymphaticnetwork.org
Lymphedema Family Study	http://www.hgen.pitt.edu/projects/lymph
Lymphedema People	http://www.lymphedemapeople.com/wiki/doku.php?id=lipedema
Lymphoedema Support Network (LSN)	http://www.lymphoedema.org
Lymphoma Research Foundation	http://www.lymphoma.org
Lynch Syndrome International	http://www.lynchcancers.com/
M.A.G.N.U.M. (The National Migraine Association)	http://www.migraines.org/
M.I.S.S. Foundation	http://www.missfoundation.org
MACS - The Micro and Anophthalmic Children's Society	http://www.macs.org.uk/
Macula.ORG	http://www.macula.org/
Macular Degeneration Foundation	http://www.eyesight.org
Macular Degeneration Partnership	http://www.AMD.org
Macular Degeneration Support	http://www.mdsupport.org
Macular Disease Society	http://www.macularisease.org/
Madisons Foundation	http://www.madisonsfoundation.org/
Malia's Cord Foundation	http://www.cordfoundation.org
Malignant Hyperthermia Association of the United States (MHAUS)	http://www.mhaus.org/
Maple Syrup Urine Disease Family Support Group	http://www.msud-support.org/
March of Dimes	http://www.marchofdimes.com/
March of Dimes	http://nacersano.marchofdimes.com
Marfan Association UK	http://www.marfan-association.org.uk/
Marigold Foundation	http://marigoldfoundation.org/
Marinesco-Sjogren Syndrome Support Group	http://www.marinesco-sjogren.org
Massachusetts Down Syndrome Congress	http://www.mdsc.org
M-CM Network	http://www.m-cm.net/
mct8.org	http://www.mct8organization.org
MdDS Balance Disorder Foundation	http://www.mddsfoundation.org
MEBO Research: Systemic Body Odor and Halitosis	http://www.meboresearch.org/aboutmebo.html
MedicAlert Foundation International	https://www.medicalert.org
Medscape Reference - Cylindroma	http://emedicine.medscape.com/article/1056630-overview#a0101
Melanoma International Foundation	http://www.melanomainternational.org

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Melnick-Needles Syndrome Support Group	http://www.melnickneedlesyndrome.com/
Melorheostosis Association	http://www.melorheostosisassociation.org
Mended Hearts, Inc.	http://www.mendedhearts.org
Meniere's Network	http://www.earfoundation.org/programs.asp?content=menieres_network
Meningitis Foundation of America (MFA)	http://www.musa.org/
Mental Health America	http://www.nmha.org/
Mesothelioma Applied Research Foundation	http://www.curemeso.org
MHE and Me- A Support Group for Kids with Multiple Hereditary Exostoses	http://www.mheandme.com/
MHE Coalition	http://www.mhecoalition.org
MHE Research Foundation	http://www.mheresearchfoundation.org/
Michael J. Fox Foundation	http://www.michaeljfox.org/
Michigan PKU & Associated Disorders, Inc.	http://www.michigan-pku.org/
Mid-Atlantic Connection for PKU and Allied Disorders	http://www.macpad.org
Midwest Women's Vascular Advocates	http://www.mwva.org
Migraine Research Foundation	http://www.migraineresearchfoundation.org
Missouri Family to Family	http://www.mofamilytofamily.org
MitoAction	http://www.mitoaction.org
Mitochondria Research Society	http://www.mitoresearch.org
MLD Foundation	http://mldfoundation.org/
Moebius Syndrome Foundation	http://www.moebiusyndrome.com
Moebius Warriors International	http://www.moebius1.org
Mollaret's Meningitis Support Group	http://mollaretsmeningitus.ning.com/
Mommies Enduring Neonatal Death	http://www.mend.org
Montgomery Heart Foundation for Cardiomyopathy	http://www.hopkinsmedicine.org/cardiomyopathy/
Motor Neurone Disease Association	http://www.mndassociation.org
Movement Disorder Society International Secretariat	http://www.movementdisorders.org/
Mowat Wilson Support	http://www.mowatwilson.org
Mowat-Wilson Syndrome Support Group	http://www.mwsupport.pwp.blueyonder.co.uk/
MPD Foundation	http://www.mpdfoundation.org
MPDSUPPORT.ORG	http://www.mpdsupport.org
MPN Research Foundation	http://www.mpnresearchfoundation.org/
MPN Education Foundation	http://www.mpdinfo.org/
MSS (Marshall-Smith Syndrome) Research Foundation	http://www.marshallsmith.org

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Mucopolidosis Type IV Foundation, Inc.	http://www.ml4.org/
Multiple Myeloma Research Foundation	http://www.themmr.org/
Multiple Sclerosis Association of America	http://www.msassociation.org
Multiple Sclerosis Foundation	http://www.msfocus.org
Muscular Dystrophy Association	http://www.mdaua.org/
Muscular Dystrophy Campaign	http://www.muscular-dystrophy.org/
Muscular Dystrophy Family Foundation	http://www.mdff.org
My Child Without Limits	http://www.mychildwithoutlimits.org/
Myasthenia Gravis Association-UK	http://www.mga-charity.org/#
Myasthenia Gravis Foundation of America, Inc.	http://www.myasthenia.org
Myasthenic Kids UK	http://myasthenickids.org/
Myelin Project	http://www.myelin.org
Myeloma Canada	http://www.myelomacanada.ca
Myeloma UK	http://www.myeloma.org.uk/
Myeloproliferative Disease Support Group Daily Digest	http://www.myeloproliferative.org
Myocarditis Foundation	http://myocarditisfoundation.org/
Myotonic Dystrophy Foundation	http://www.myotonic.org
Myotonic Dystrophy Support Group	http://www.myotonicdystrophysupportgroup.org/
Myotubular Myopathy Resource Group	http://www.mtmrg.org
Myotubular Trust	http://www.myotubulartrust.com
Nail Patella Syndrome UK	http://www.npsuk.org
Nail Patella Syndrome Worldwide	http://www.npsw.org
Narcolepsy Network, Inc.	http://www.narcolepsynetwork.org
Nathan's Battle Foundation	http://www.nathansbattle.com
National Adrenal Diseases Foundation	http://www.nadf.us/
National Alliance for Eye and Vision Research (NAEVR)	http://www.eyeresearch.org/
National Alliance of Breast Cancer Organizations	http://www.nbcam.org
National Alliance on Mental Illness (NAMI)	http://www.nami.org/
National Alopecia Areata Foundation (NAAF)	http://www.naaf.org
National Ankylosing Spondylitis Society	http://www.nass.co.uk
National Aphasia Association	http://www.aphasia.org
National Association Anorexia Nervosa & Associated Disorders, Inc.	http://www.anad.org
National Association for Continence (NAFC)	http://www.nafc.org/

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National Association for Down Syndrome	http://www.nads.org
National Association for Parents of Children with Visual Impairments (NAPVI)	http://www.spedex.com/napvi/
National Association for Parents of the Visually Impaired	http://www.napvi.org
National Association for Pseudoxanthoma Elasticum, Inc. (NAPE)	http://www.pxenape.org
National Association of the Deaf	http://www.nad.org
National Ataxia Foundation	http://www.ataxia.org
National Blood Clot Alliance	http://stoptheclot.org/
National Bone Marrow Transplant Link	http://www.nbmtlink.org
National Brachial Plexus/Erb's Palsy Association, Inc.	http://www.nbpepa.org
National Brain Tumor Society	http://www.brainumor.org
National Breast Cancer Coalition	http://www.natlbcc.org
National Center for Learning Disabilities	http://www.nclld.org
National Chronic Fatigue Syndrome and Fibromyalgia Association	http://www.ncfsfa.org
National Consortium On Deaf-Blindness	http://nationaldb.org
National Down Syndrome Adoption Network	http://www.ndsan.org
National Down Syndrome Congress	http://www.ndscenter.org
National Down Syndrome Society	http://www.ndss.org
National Dysautonomia Research Foundation	http://www.ndrf.org
National Eczema Association	http://www.nationaleczema.org
National Endowment for Alzheimer's Research	http://www.memorymatters.org
National Eosinophilia-Myalgia Syndrome Network	http://www.nemsn.org
National Fabry Disease Foundation	http://www.fabrydisease.org/
National Family Caregivers Association	http://www.thefamilycaregiver.org
National Federation of the Blind	http://www.nfb.org/
National Fibromyalgia Association	http://www.fmaware.org
National Fibromyalgia Partnership, Inc.	http://www.fmpartnership.org
National Fibromyalgia Research Association	http://www.nfra.net
National Foundation for Celiac Awareness	http://www.celiaccentral.org/
National Foundation for Ectodermal Dysplasias	http://nfed.org/
National Foundation for Facial Reconstruction	http://www.nffr.org
National Foundation for Infectious Diseases	http://www.nfid.org
National Fragile X Foundation	http://www.FragileX.org

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National Gaucher Foundation (NGF)	http://www.gaucherdisease.org/
National Gaucher Foundation of Canada	http://www.gauchercanada.ca/
National Headache Foundation	http://www.headaches.org
National Headache Foundation	http://www.headaches.org
National Hemophilia Foundation	http://www.hemophilia.org/
National Hospice and Palliative Care Organization /Natl. Hospice Foundation	http://www.nhpco.org
National Hydrocephalus Foundation	http://nhfonline.org
National Institute of Dental and Craniofacial Research	http://www.nidcr.nih.gov/
National Keratoconus Foundation	http://www.nkcf.org
National Kidney Center	http://www.nationalkidneycenter.org
National Kidney Foundation, Inc.	http://www.kidney.org
National Leiomyosarcoma Foundation	http://www.nlmfsf.org
National Lichen Sclerosus Support Group	http://www.lichensclerosus.org/
National Lipedema Association	http://www.lipedema.org
National Lung Cancer Partnership	http://www.nationallungcancerpartnership.org
National Lymphedema Network (NLN)	http://www.lymphnet.org
National Marden Walker Organization	http://www.mardenwalker.org
National Marfan Foundation	http://www.marfan.org
National MPS Society	http://www.mppsociety.org
National Multiple Sclerosis Society	http://www.nationalmssociety.org
National Multiple Sclerosis Society	http://www.nationalmssociety.org
National Neurofibromatosis Foundation	http://www.nf.org
National Neutropenia Network	http://www.neutropenianet.org
National Niemann-Pick Disease Foundation, Inc.	http://www.nnpdf.org
National Organization for Rare Disorders (NORD)	http://www.rarediseases.org
National Organization of Disorders of the Corpus Callosum	http://www.nodcc.org
National Organization of Parents of Blind Children	http://www.nfb.org/parents-and-teachers
National Organization of Vascular Anomalies	http://www.novanews.org
National Organization on Fetal Alcohol Syndrome (NOFAS)	http://www.nofas.org/
National Osteonecrosis Foundation	http://www.nonf.org/index.html
National Osteoporosis Foundation	http://www.nof.org/
National Ovarian Cancer Coalition	http://www.ovarian.org/

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National Pancreas Foundation	http://pancreasfoundation.org/
National Parkinson Foundation, Inc.	http://www.parkinson.org/
National PKU Alliance	http://www.npkua.org/
National PKU News	http://www.pkunews.org/
National Primary Immunodeficiency Resource Center	http://www.info4pi.org
National Psoriasis Foundation	http://www.psoriasis.org
National Rehabilitation Information Center	http://www.naric.com/
National Resource Center on ADHD	http://www.help4adhd.org
National Respite Network and Resource Center	http://www.archrespite.org
National Reye's Syndrome Foundation	http://www.reyessyndrome.org/
National Rosacea Society	http://www.rosacea.org/index.php
National Scoliosis Foundation	http://www.scoliosis.org/
National Shingles Foundation	http://www.vzvfoundation.org/
National Sleep Foundation	http://www.sleepfoundation.org
National Society for Phenylketonuria	http://www.nspku.org/
National Spasmodic Dysphonia Association	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/
National Tay-Sachs and Allied Diseases Association	http://www.ntsad.org
National Tay-Sachs and Allied Diseases Association, Inc	http://www.ntsad.org/index.php/the-diseases
National Urea Cycle Disorders Foundation	http://www.nucdf.org
National Uterine Fibroids Foundation	http://www.nuff.org
National Vitiligo Foundation Inc	http://www.mynvfi.org
National Vulvodynia Association	http://www.nva.org
NBIA Disorders Association	http://www.nbiadisorders.org
NephCure Foundation	http://www.nephcure.org/
Nephrogenic Diabetes Insipidus Foundation	http://www.ndif.org/public/pages/36-Welcome_to_NDI_Foundation
Nephrogenic Diabetes Insipidus Network	http://www.ndif.org
NET Patient Foundation	http://www.netpatientfoundation.org/
Neurofibromatosis Mid-Atlantic	http://www.nfmidatlantic.org/
Neurofibromatosis Midwest	http://www.nfmidwest.org

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Neurofibromatosis Network	http://www.nfnetwork.org/
Neurofibromatosis, Inc. California	http://www.nfcalifornia.org
Neurofibromatosis, Inc., Northeast	http://www.nfincne.org
Neuromuscular Disease Association of China	http://www.mdachina.org
Neuromuscular Disease Foundation	http://www.ndf-hibm.org/
Neuropathy Association	http://www.neuropathy.org/
Neutropenia Support Association, Inc.	http://www.neutropenia.ca
Nevus Network	http://www.nevusnetwork.org
Nevus Outreach, Inc.	http://www.nevus.org/
Niemann-Pick Disease Group (UK)	http://www.niemannpick.org.uk
NIH Clinical Trials and You	http://www.nih.gov/health/clinicaltrials/index.htm
No Stomach For Cancer	http://www.nostomachforcancer.org/
No Stomach For Cancer	http://www.nostomachforcancer.org
Nonketotic Hyperglycinemia International Family Network	http://www.nkh-network.org
Norma Livingston Ovarian Cancer Foundation	http://www.nlovca.org
Norrie Disease Association	http://www.norriedisease.org/
NORSEpilepsy.org	http://norseepilepsy.org/
Northwest Parkinson's Foundation	http://www.nwpcf.org
Nuclease Immune Mediated Brain & Lupus-like Conditions	http://www.nimbl.eu/ni/Home
O.A.S.I.S. Online Asperger Syndrome Information and Support	http://www.aspergersyndrome.org
Ocular Immunology and Uveitis Foundation	http://www.uveitis.org
Ocular Melanoma Foundation	http://www.ocularmelanoma.org/home.htm#
Oklahoma Family Network	http://www.oklahomafamilynetwork.org
Online Mendelian Inheritance in Man (OMIM)	http://www.ncbi.nlm.nih.gov/entrez/dispomim.cgi?id=603358
Opsoclonus - Myoclonus U.S.A. and International	http://www.omsusa.org/index.htm
Organic Acidemia Association	http://www.oaanews.org/
Organización Argentina "Gente Bajita"	http://www.gentebajita.org.ar/
Organización Mexicana de Enfermedades Raras (OMER)	http://omer.drupalgardens.com/es/node
Organization for Autism Research	http://www.researchautism.org/
Organization for Understanding Cluster Headaches (O.U.C.H.)	http://www.ouch-us.org/index.shtml
Orthostatic Tremor - information and forum	http://www.orthostatictremor.org/

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Osteogenesis Imperfecta Foundation	http://www.oif.org/site/PageServer
Osteogenesis Imperfecta Foundation	http://www.oif.org
Oto-PalatelDigital Syndrome Family Research Network	http://www.opdsyndrome.org/
Ovarian Cancer National Alliance	http://www.ovariancancer.org/
Oxalosis and Hyperoxaluria Foundation (OHF)	http://www.ohf.org
Pachyonychia Congenita Project	http://www.pachyonychia.org/
Paget Foundation	http://www.paget.org
Pain Relief Foundation	http://www.painrelieffoundation.org.uk/
PAN Support Network 2009	http://www.pansupportnetwork.org/
Pancreatic Cancer Action Network	http://www.pancan.org/
Panniculitis Support Group	http://www.groups.yahoo.com/group/panniculitis/
Parent Project Muscular Dystrophy	http://www.parentprojectmd.org
Parent Technical Assistance Center Network	http://www.parentcenternetwork.org/parentcenterlisting.html
PARENT TO PARENT OF NYS	http://www.parenttoparentnys.org/
Parents and Researchers Interested in Smith-Magenis Syndrome (PRISMS)	http://www.prisms.org
Parents of Infants and Children with Kernicterus	http://www.PICKonline.org
Parkinson's Disease Foundation, Inc	http://www.pdf.org
Parkinson's Patients Support Groups, Inc.	http://www.ppsg.org
Parry-Romberg Syndrome Resource, Inc.	http://www.prsresource.com
Pathfinders for Autism	http://www.pathfindersforautism.org
Patients Connect	http://patients-connect.com/
PCDH19 Alliance	http://www.pcdh19info.org
Pedal with Pete (Cerebral Palsy)	http://pedal-with-pete.org/cerebral-palsy/
Pedal with Pete [For Research on Cerebral Palsy]	http://www.pedalwithpete.com
Pediatric Adolescent Gastroesophageal Reflux Association	http://www.reflux.org
Pediatric Brain Tumor Foundation of the United States	http://www.pbtfus.org
Pediatric Inflammatory Bowel Disease Foundation	http://pedsibd.org/
Pediatric Neurotransmitter Disease Association	http://www.pndassoc.org/
Pelizaeus-Merzbacher Disease Foundation	http://www.pmdfoundation.org
Periodic Paralysis Association	http://www.periodicparalysis.org
Periodic Paralysis News Desk	http://www.hkpp.org
PFIC A Resource for Parents	http://www.PFIC.org
PGAD Support	http://www.psas-support.com/

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PHCentral	http://www.phcentral.org
Phelan-McDermid Syndrome Foundation	http://www.22q13.org
Pheo Para Troopers	http://www.pheoparatroopers.org/
Pierre Robin Network	http://www.pierrerobin.org/
Pioneering Unique Cures for Kids	http://www.puckfund.org
Pitt Hopkins Research Foundation	http://pitthopkins.org/
Pitt Hopkins Syndrome Support Group	http://groups.google.com/group/pitt-hopkins
Pituitary Network Association	http://www.pituitary.org/
Pityriasis Rubra Pilaris (PRP) Support Group (on-line)	http://www.prp-support.org
PKD Foundation	http://www.pkdcure.org
PKS Kids	http://www.pskkids.net
PKU (Phenylketonuria) and Allied Disorders	http://www.canpku.org/
Platelet Disorder Support Association	http://www.pdsa.org/
PMG Awareness Organization, Inc.	http://pmgawareness.org/
PML Consortium	http://pmlconsortium.org
PMP Awareness Organization	http://www.pmpawareness.org/
PMP Pals	http://www.pmppals.org
PMP Research Foundation, Inc.	http://www.pmpcure.org
Poland Syndrome Support Group	http://www.pssgcharity.org/
Polio Experience Network	http://www.polionet.org/
Polycystic Kidney Disease Charity	http://www.pkdcharity.org.uk
Polycystic Ovarian Syndrome Association	http://www.pcosupport.org
Post Orgasmic Illness Syndrome (POIS) Forum	http://poiscenter.com/forums/index.php
Post-Finasteride Syndrome Foundation	http://www.pfsfoundation.org/
Post-Polio Health International	http://www.post-polio.org
Potentials Foundation - A Cause for Chloe	http://www.potentialsfoundation.org/
Potocki-Lupski Syndrome Outreach	http://potockilupskisyndrome.org/
Potocki-Lupski Syndrome Outreach Foundation, Inc	http://www.PTLSfoundation.org
Prader-Willi Syndrome Association	http://www.pwsausa.org/
Prader-Willi Syndrome Association-Kansas	http://www.pwsa-kansas.org
Preeclampsia Foundation	http://www.preeclampsia.org
Prevent Blindness America	http://www.preventblindness.org/
Primary Ciliary Dyskinesia (PCD) Foundation	http://www.pcdfoundation.org

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Primary Ciliary Dyskinesia Family Support Group	http://www.pcdsupport.org.uk
Primary Immunodeficiency Association (UK)	http://www.pia.org.uk/
Progeria Research Foundation, Inc.	http://www.progeriaresearch.org
Progressive Osseous Heteroplasia Association	http://www.pohdisease.org/
ProjectAccept.org	http://www.projectaccept.org
Propionic Acidemia Foundation	http://www.pafoundation.com/
Propionic Acidemia Research Network	http://www.paresearch.org
Protein S Deficiency and Thombophilia (online support)	http://proteinsdeficiency.com/
Proteus Syndrome Foundation	http://www.proteus-syndrome.org
Proteus Syndrome Foundation, UK	http://www.proteus-syndrome.org.uk/
Prune Belly Syndrome Network, Inc.	http://www.prunebelly.org
PSC Partners Seeking a Cure	http://www.pscpartners.org/
Pseudotumor Cerebri Support Network	http://www.angelfire.com/ok/PTCSupportNetwork/
Pseudoxanthoma Elasticum (PXE) Support Group (PiXiE)	http://www.pxe.org.uk/
PubMed Central website	http://www.pubmedcentral.nih.gov
Pull-thru Network	http://www.pullthrunetwork.org/
Pulmonary Fibrosis Foundation	http://www.pulmonaryfibrosis.org/
Pulmonary Hypertension Association	http://www.phassociation.org/Page.aspx?pid=197
Purine Research Society	http://www.purineresearchsociety.org/
PVNH Support & Awareness	http://pvnhsupport.com/
PXE International	http://www.pxe.org
QT Syndrome.ch	http://www.qtsyndrome.ch/
Rachel's Well	http://www.rachelswell.org
Ramon Brugada Sr Foundation	http://www.brugada.org
Rare Anemias Foundation	http://www.rareanemias.org
Rare Cancer Alliance	http://www.rare-cancer.org
Rare Cancers Europe	http://www.rarecancerseurope.org
Rare Disease Legislative Advocates	http://rareadvocates.org/
RareChemo.org website	http://www.rarechemo.org
RareConnect	https://www.rareconnect.org/
RareShare	http://www.rareshare.org/
RASopathies Network U.S.A.	http://rasopathiesnet.org
Raynaud's & Scleroderma Association	http://www.raynauds.org.uk

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Raynaud's Association	http://www.raynauds.org/
RDH12 Fund for Sight	http://www.rdh12.org/
RE Children's Project	http://rechildrens.com/
R-E Children's Project	http://www.rechildrens.org/blog/
RE Children's Project Inc	http://rechildrens.org/
Reach Out for Youth With Ileitis and Colitis Inc.	http://www.reachoutforyouth.org/
Reach: The Association for Children with Hand or Arm Deficiency	http://www.reach.org.uk
Recurrent Respiratory Papillomatosis Foundation (RRPF)	http://www.rrpf.org/
Red de Amor	http://www.reddeamor.org
Reflex Sympathetic Dystrophy Syndrome Association of America (RSDSA)	http://www.rsds.org/
Relapsing Polychondritis Awareness and Support Foundation, Inc	http://www.polychondritis.org
Related Brain Diseases	http://www.psp.org/
Renal Support Network	http://www.rsnhope.org/
ResearchMatch	https://www.researchmatch.org/?route=gard
Resolve: The National Infertility Association	http://www.resolve.org
Rest Ministries, Inc.	http://www.restministries.org
Restricted Growth Association	http://www.restrictedgrowth.co.uk
Retina International	http://www.retina-international.org
Retinitis Pigmentosa International	http://www.rpinternational.org
Rett UK	http://www.rettuk.org/rettuk-public/rettuk.html
Rheumatic Heart Disease Network	http://www.world-heart-federation.org/rhd
Rhode Island Rare Disease Foundation	http://www.rirdf.org
Ring Chromosome 20 Foundation	http://www.ring20.org
Robinow Syndrome Foundation	http://www.robinow.org/
Rocky Mountain Down Syndrome Association	http://www.rmdsa.org/
ROPARD: The Association for Retinopathy of Prematurity and Related Diseases	http://www.ropard.org
Rothmund-Thomson Syndrome Foundation	http://rtsplace.org/
Royal National Institute of Blind People	http://www.rnib.org.uk/Pages/Home.aspx
RTS Canada	http://www.rtscanada.org/what_is_canada.htm
Rubinstein Taybi Syndrome Children's Foundation	http://www.facebook.com/RTSCF
Rubinstein-Taybi Syndrome Website	http://www.rubinstein-taybi.org/

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SADS Foundation	http://www.sads.org/StopSADS
Sarcoid Networking Association	http://www.sarcoidosisnetwork.org
Sarcoidosis Research Institute	http://www.sarcoidosisresearch.org
Sarcoma Alliance	http://www.sarcomaalliance.org
Sarcoma Foundation of America	http://www.curesarcoma.org
Save Babies Through Screening Foundation, Inc	http://www.savebabies.org
SCAD Research	http://www.scadresearch.org/
Schinz-Giedion Syndrome Patient Support Group	http://www.schinz-giedion.org/
Schiz Kidz Buddies Online Support Group for Schizencephaly	http://www.schizkidzbuddies.com/
Schwannoma Patient Support Group	http://anausa.org/
Scleroderma Foundation	http://www.scleroderma.org/
Scleroderma Research Foundation	http://www.srfcure.org
Scleroderma Society of Canada	http://www.scleroderma.ca/
Scoliosis Research Society	http://www.srs.org
Scottish Motor Neurone Disease Association	http://www.scotmnd.org.uk
Selective Mutism Foundation, Inc.	http://www.selectivemutismfoundation.org
Self Help Queensland, Inc.	http://www.selfhelpqld.org.au
Severe Combined Immunodeficiencies Patient Support	http://www.scid.net/
SHARE	http://www.sharecancersupport.org
SHARE - Pregnancy and Infant Loss Support, Inc.	http://www.nationalshare.org/
Share and Care Cockayne Syndrome Network Inc.	http://cockaynesyndrome.net
Sharsheret	http://www.sharsheret.org
Shwachman-Diamond America	http://www.shwachmandiamondamerica.org/index.html
Shwachman-Diamond Syndrome - Australia, Inc.	http://www.shwachmandiamondsyndrome.com.au
Shwachman-Diamond Syndrome Foundation	http://www.shwachman-diamond.org
Sibling Support Project	http://www.siblingsupport.org/
Sickle Cell Disease Association of America	http://www.sicklecelldisease.org/
Sickle Cell Disease Association of America, Inc-Eastern NC Chapter	http://www.sicklecelleasternnc.org
Sickle Cell Disease Foundation of California	http://www.scdfc.org/
Sickle Cell/Thalassemia Patients Network	http://sctpn.org
Sidelines High Risk Pregnancy Support	http://www.sidelines.org
Simpson-Golabi-Behmel Syndrome	http://www.sickkids.ca/
SÍNDROME X-FRÁGIL en Argentina	http://www.xfragil.com.ar

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Sjögren's Syndrome Foundation	http://www.sjogrens.org/
Sjogren's World	http://www.sjogrensworld.org
Smith-Lemli-Opitz/RSH Foundation	http://www.smithlempiopitz.org
Smith-Magenis Syndrome Foundation	http://www.smith-magenis.co.uk
SMS Research Foundation	http://www.smsresearchfoundation.org
Sneddon's Foundation	http://www.sneddonsyndrome.org/
Sociedad Española de Errores Innatos del Metabolismo	http://eimaep.com/
Society for Mucopolysaccharide (MPS) Diseases	http://www.mpsociety.co.uk
Society for Vascular Surgery	http://www.vascularweb.org/index.html
Soft Bones Inc.	http://www.softbones.org
Sotos Syndrome Support Association	http://www.sotosyndrome.org/
Sotos Syndrome Support Association of Canada	http://www.sssac.com
Spasmodic Torticollis ST/Dystonia, Inc.	http://www.spasmodictorticollis.org
Spastic Paraplegia Foundation	http://www.sp-foundation.org
Spina Bifida & Hydrocephalus Association of Ontario	http://www.sbhao.on.ca
Spina Bifida Association	http://www.spinabifidaassociation.org
Spina Bifida Resource Network	http://www.thesbrn.org
Spinal Muscular Atrophy Foundation	http://www.smafoundation.org
Spondylitis Association of America	http://www.spondylitis.org/
Starkey Hearing Foundation	http://www.starkeyhearingfoundation.org/
Starlight Children's Foundation	http://www.Starlight.org
STARS- Syncope Trust and Reflex Anoxic Seizures	http://www.stars.org.uk/
Statewide Parent Advocacy Network	http://www.spanadvocacy.org/
Stevens Johnson Syndrome Foundation	http://www.sjsupport.org/
Stickler Involved People	http://www.sticklers.org
Stone Circle of Friends	http://www.stonecircleoffriends.com/
StopCAIDnow	http://www.stopcaidnow.org/
Stupid Cancer	http://stupidcancer.org
Sturge-Weber Foundation	http://www.sturge-weber.org
Sturge-Weber Foundation UK	http://www.sturgeweber.org.uk/
Sudden Arrhythmia Death Syndromes Foundation	http://www.sads.org
SuperHands	http://www.superhands.us/
Support For People With Oral And Head And Neck Cancer	http://www.spohnc.org

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Support Group for DiGeorge and Velo-Cardio-Facial Syndromes	http://www.vcfsconnect.org/index.php?option=com_content&task=view&id=17&Itemid=33
Support Organization for Trisomy 18, 13, and Related Disorders (SOFT)	http://www.trisomy.org/index.php
Supporting Aussie Kids with Kabuki Syndrome	http://www.sakks.org
Supporting Families with Koolen-de Vries Syndrome	http://www.supportingkdvs.com/
Syndromes Without A Name USA	http://www.undiagnosed-usa.org
Taiwan Foundation for Rare Disorders	http://www.tfrd.org.tw/english/
Taking Control of Your Diabetes	http://www.tcoyd.org
TAR Syndrome Support Group	http://www.ivh.se/TAR/
Tarlov Cyst Disease Foundation	http://www.tarlovcystfoundation.org
Team Sanfilippo Foundation	http://www.teamsanfilippo.org/
TEF VATER International Support Network	http://www.tefvater.org
Testicular Cancer Society	http://www.testicularcancersociety.org/
Tetrasomy 18p Canada	http://www.tetrasomy18p.ca/
Texas Neurofibromatosis Foundation	http://www.texasnf.org
Thalassaemia International Federation	http://www.thalassaemia.org.cy
The Adrenoleukodystrophy Foundation	http://www.aldfoundation.org
The Alkaptonuria Society	http://www.alkaptonuria.info/en/home.php
The ALS Association	http://www.alsa.org
The American Porphyria Foundation	http://www.porphyrifoundation.com
The Arc of East Central Iowa	http://www.arceci.org
The Arc of Illinois	http://www.thearcofil.org/
The Arc of the United States	http://www.thearc.org
The Arms of an Angel- Trisomy 18 Association	http://www.trisomy18dallas.org
The Arthritis Society	http://www.arthritis.ca/custom%20home/default.asp?s=1
The Association for Fighting Best Disease	http://www.best.org.il/
The Bachmann-Strauss Dystonia & Parkinson Foundation	https://www.dystonia-parkinson.org
The Balanced Mind Foundation	http://www.thebalancedmind.org
The Bartter Site	http://barttersite.org/
The bonnie j addario lung cancer foundation	http://www.lungcancerfoundation.org
The British Columbia Neurofibromatosis Foundation	http://www.bcnf.bc.ca
The Brittle Bone Society	http://www.brittlebone.org/
The Carcinoid Cancer Foundation, Inc.	http://www.carcinoid.org/

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The Center for Peripheral Neuropathy	http://peripheralneuropathycenter.uchicago.edu/
The Children's Heart Foundation	http://www.childrensheartfoundation.org/
The Children's Tumor Foundation	http://www.ctf.org/
The Children's Tumor Foundation	http://www.ctf.org/
The Cochrane Collaboration	http://cfgd.cochrane.org
The Cortical Foundation	http://cortfoundation.org
The Degos Disease Support Network Web site	http://www.degosdisease.com/
The Dempster Family Foundation	http://www.DempsterFoundation.org
The Digestive Disease National Coalition	http://www.ddnc.org/
The Ectodermal Dysplasia Society	http://www.ectodermaldysplasia.org/
The Endocrine Society	http://www.endo-society.org
The Feingold Center for Children	http://www.thefeingoldcenter.org/
The FH Foundation	http://www.thefhfoundation.org/
The Fibromuscular Dysplasia Society of America (FMDSA)	http://www.fmdsa.org/
The FM Foundation	http://thefmfoundation.org/index.html
The Focus Foundation	http://www.thefocusfoundation.org/FF/index.php
The Foundation for Children with Atypical HUS	http://www.atypicalhus.org
The Fragile X Society	http://www.fragilex.org.uk
The G6PD Favism Association	http://www.g6pd.org/favism/english/
The Glaucoma Foundation	http://www.glaucomafoundation.org
The Haemophilia Society	http://www.haemophilia.org.uk/
The Hageman Foundation	http://hagemanfoundation.org/
The Hemispherectomy Foundation	http://hemifoundation.intuitwebsites.com/welcome.html
The Heterotaxy Network	http://www.theheterotaxynetwork.org
The Hormone Foundation	http://www.hormone.org
The Hughes Syndrome Foundation	http://www.hughes-syndrome.org/
The Hyperacusis Network	http://www.hyperacusis.net/
The International 22q11.2 Deletion Syndrome Foundation, Inc.	http://www.22q.org
The International Advocates for Glycoprotein Storage Diseases (ISM RD)	http://www.ismrd.org/
The International Association for CFS/ME	http://www.iacfsme.org/
The InterNational Council on Infertility Information Dissemination, Inc.	http://www.inciid.org
The International Ocular Inflammation Society	http://iois.in/

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The Jack McGovern Coats Disease Foundation	http://www.coatsdiseasefoundation.org
The Jennifer Trust for Spinal Muscular Atrophy	http://www.jtsma.org.uk
The J-Pouch Group	http://www.jpouch.org/
The Kidney Foundation of Canada	http://www.kidney.on.ca
The Kimberly D. Holland Hodgkins Disease Foundation	http://www.hodgkinsfoundation.org
The LAM Foundation	http://www.thelamfoundation.org/about-lam.html
The Lee Spark NF Foundation	http://nfsuk.org.uk/
The Leukemia and Lymphoma Society	http://www.leukemia.org/
The Liddy Shriver Sarcoma Initiative	http://sarcomahelp.org/
The Life Raft Group	http://www.liferaftgroup.org
The Lustgarten Foundation	http://www.lustgarten.org
The MAGIC Foundation	http://magicfoundation.org
The Mastocytosis Society	http://www.tmsforacure.org/
The Migraine Trust	http://www.migrainetrust.org/
The Multiple System Atrophy Coalition	http://www.multiple-system-atrophy.org/
The Myositis Association	http://www.myositis.org
The National Breast Cancer Coalition/Fund	http://www.stopbreastcancer.org/
The National Children's Cancer Society	http://www.thenccs.org
The National Coalition for Cancer Survivorship	http://www.canceradvocacy.org
The National Necrotizing Fasciitis Foundation	http://www.nnff.org/
The National Organization of Albinism and Hypopigmentation (NOAH)	http://www.albinism.org
The Neurofibromatosis Association	http://www.nfauk.org
The Neuropathy Association	http://www.neuropathy.org
The NF1 Patient Research Initiative (NPRI)	https://nf1registry.wustl.edu/
The Opsoclonus Myoclonus Syndrome Support Network, Inc.	http://www.omsupportnetwork.org/
The Oral Cancer Foundation	http://oralcancerfoundation.org
The Original Clostridium Difficile Support Group	http://www.cdiffsupport.com/
The Pancreatitis Supporters Network	http://www.pancreatitis.org.uk/
The Patty Brisben Foundation for Women's Sexual Health	http://www.pattybrisbenfoundation.com/
The PBCers Organization	http://www.pbcers.org/
The Pituitary Foundation	http://www.pituitary.org.uk/
The Pituitary Society	http://www.pituitarysociety.org

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The PSP Association	http://www.pspeur.org
The Rarer Cancers Forum	http://www.rarercancers.org.uk
The Romberg's Connection	http://www.therombergsconnection.com/
The Sickle Cell Information Center	http://www.scinfo.org
The Skin Cancer Foundation	http://www.skincancer.org/
The Society for Developmental and Behavioral Pediatrics	http://www.sdbp.org/index.cfm
The Society for Muscular Dystrophy Information International	http://www.nsnet.org/smdi/
The Stennis Foundation	http://www.stennisfoundation.org
The Stop ALD Foundation	http://www.stopald.org
The Stuttering Foundation of America	http://www.stutteringhelp.org/
The Susan G. Komen Breast Cancer Foundation	http://ww5.komen.org/
The Twin to Twin Transfusion Syndrome Foundation	http://www.ttsfoundation.org/
The VHL Family Alliance	http://www.vhl.org
ThyCa: Thyroid Cancer Survivors' Association, Inc.	http://www.thyca.org
Thyroid Cancer Forum-UK	http://www.thyroid-cancer-forum-uk.org
TMJ Association, Ltd.	http://tmj.org
TNA -- Facial Pain Association (formerly the Trigeminal Neuralgia Association)	http://www.endthepain.org
TNA The Facial Pain Association	http://www.fpa-support.org/
Together for the research on PCDH19 (Italy)	http://www.pcdh19research.org/ENG/index_ENG.html
Tourette Syndrome Association	http://tsa-usa.org
Tourette Syndrome Foundation of Canada	http://www.tourette.ca/
Townes-Brocks Syndrome International Support Network	http://health.groups.yahoo.com/group/Townes-Brocks-Syndrome/
Transverse Myelitis Association	http://www.myelitis.org
Treacher Collins Family Support Group	http://www.treachercollins.net/
TREAT-NMD	http://www.treat-nmd.eu/
Tremor Action Network	http://www.tremoraction.org
Trichotillomania Learning Center	http://www.trich.org/
Trisomy 18 Foundation	http://www.trisomy18.org/site/PageServer
Trisomy 9 International Parent Support	http://www.trisomy9.org/9tips.htm
Tuberous Sclerosis Alliance	http://www.tsalliance.org/
Turner Syndrome Aorta Dissection Registry	https://www.ohsu.edu/pedscardturner/TSform-test.htm
Turner Syndrome Foundation	http://www.turnersyndromefoundation.org/

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Turner Syndrome Society of the United States	http://www.turnersyndrome.org/
Turner Syndrome Support Society	http://www.tss.org.uk/
UCSF Fibrodysplasia Ossificans Progressiva Clinic	http://www.ucsfbenioffchildrens.org/conditions/fibrodysplasia_ossificans_progressiva/index.html
UKD Foundation	http://www.ukdcure.org/
Unique – Rare Chromosome Disorder Support Group	http://www.rarechromo.org
United Brachial Plexus Network, Inc.	http://www.ubpn.org
United Cerebral Palsy (UCP)	http://www.ucp.org
United Cerebral Palsy Association, Inc.	http://www.ucpa.org
United Leukodystrophy Foundation (ULF)	http://www.ulf.org/
United Mitochondrial Disease Foundation	http://www.umdf.org
United Pompe Foundation	http://www.unitedpompe.com/index.cfm
United Spinal Association	http://www.unitedspinal.org
United States Immunodeficiency Network (USIDNET)	http://www.usidnet.org
Urology Care Foundation	http://www.urologyhealth.org/
US Hereditary Angioedema Association, Inc.	http://www.haea.org
Vascular Birthmarks Foundation	http://birthmark.org/
Vascular Disease Foundation	http://vasculardisease.org/
Vasculitis Foundation	http://www.vasculitisfoundation.org/
Vasculitis Foundation Canada	http://www.vasculitis.ca/
VCFS 22q11 Foundation	http://www.vcfsfa.org.au
Velo-Cardio-Facial Syndrome Educational Foundation	http://www.vcfsef.org
Vestibular Disorders Association	http://www.vestibular.org
Virginia Breast Cancer Foundation	http://www.vbcf.org
Vision of Children Foundation (VOC)	http://www.visionofchildren.org
VISIONS: Services for the Blind and Visually Impaired	http://www.visionsvcb.org
Vital Options International	http://www.vitaloptions.org
Vitiligo Research Foundation (VR Foundation)	http://vrfoundation.org
Vitiligo Support International	http://www.vitiligosupport.org/front_page.cfm
VOR-Speaking up for people with intellectual & developmental disabilities	http://www.vor.net
Wagner Syndrome Website	http://www.wagnersyndrome.eu/
Wake Up Narcolepsy, Inc.	http://www.wakeupnarcolepsy.org/
Washington State Fathers Network	http://www.fathersnetwork.org
Wendt Center for Loss and Healing	http://wendtcenter.org/

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Williams Syndrome Association	http://www.williams-syndrome.org
Williams Syndrome Changing Lives Foundation	http://www.wschanginglives.org/
Williams Syndrome Family of Hope	http://www.wsfamilyofhope.org
Willis-Ekbom Disease Foundation	http://www.willis-ekbom.org
Wilson Disease Association International	http://www.wilsonsdisease.org
Wisconsin ME/CFS Association, Inc.?	http://www.wicfs-me.org/
Wiskott-Aldrich Foundation	http://www.wiskott.org
Wolf-Hirschhorn Syndrome Trust (UK)	http://www.whs4pminus.co.uk/
Wolfram Syndrome UK Support Group	http://www.wolframsyndrome.co.uk/
Working for A World Without Leprosy	http://www.ilep.org.uk/links/
World Arnold Chiari Malformation (ACM) Association	http://www.pressenter.com/~wacma/
World Craniofacial Foundation	http://www.worldcf.org/
World Federation of Hemophilia	http://www.wfh.org/
Worldwide Lichen Sclerosus Support	http://lichensclerosus.org/
Worldwide Society of Wolfram Syndrome Families	http://www.wolframsyndrome.org/
Wynne Foundation Inc.	http://www.wynnefoundation.org
Xeroderma Pigmentosum Family Support Group	http://www.xpfamilysupport.org
Xeroderma Pigmentosum Society, Inc (XP Society)	http://www.xps.org
XLH (X-linked Hypophosphatemia) Network, Inc.	http://www.xlhnetwork.org/
XLP Research Trust	http://www.xlpresearchtrust.org/
XP Family Support Group	http://xpfamilysupport.com/
XP Support Group	http://www.xpsupportgroup.org.uk
XXYY Project Organization	http://xxyysyndrome.org/english.php
Yahoo! Duane Syndrome Online Support Group	http://health.groups.yahoo.com/group/duanes/
Yahoo! TarSupport	http://health.groups.yahoo.com/group/TarSupport
Young Survival Coalition	http://www.youngsurvival.org/
Zellweger Baby Support Network	http://zbsn.org/