



The Global Advocacy Alliance is made up of foundations, organizations and support groups that have committed to collaborating with Global Genes and other nonprofit foundations in order to create a stronger, collective voice in the rare disease community.

Organization	Website	Rare Disease Served
17q12 Foundation	<a href="http://chromo17q12.org">chromo17q12.org</a>	Chromosome 17q12 Duplication Syndrome and Chromosome 17q12 Deletion Syndrome
A Kid Again	<a href="https://akidagain.org/">https://akidagain.org/</a>	Life Threatening Conditions Approved by the Doctor on our Board
AADC Family Network	<a href="https://www.aadcfamilynetwork.org/">https://www.aadcfamilynetwork.org/</a>	AADC (Aromatic L Amino Acid Decarboxylase Deficiency)
Abrafeu - Brazilian Association for Facioscapulohumeral Dystrophy	<a href="http://abrafeu.org.br">http://abrafeu.org.br</a>	Facioscapulohumeral Dystrophy - FSHD
Accessia Health Foundation	<a href="http://www.accessiahealth.com">www.accessiahealth.com</a>	Rare and Chronic Diseases
ACMCRN Arachnoiditis & Chronic Meningitis Collaborative Research Network	<a href="http://www.acmcrn.org">www.acmcrn.org</a>	Arachnoiditis
Adrenal Alternatives Foundation	<a href="https://adrenalalternatives.com/">https://adrenalalternatives.com/</a>	Adrenal Diseases
Adrenal Insufficiency United	<a href="https://www.aiunited.org">https://www.aiunited.org</a>	Adrenal Insufficiency
Adult Polyglucosan Body Disease Research Foundation	<a href="http://www.APBDRF.org">www.APBDRF.org</a>	Adult Polyglucosan Body Disease
Aicardi-Goutières Syndrome Advocacy Association (AGSAA)	<a href="https://agsaa.org/">https://agsaa.org/</a>	Aicardi-Goutieres Syndrome
Alaafia Women	<a href="http://strengthinsicklecell.com">strengthinsicklecell.com</a>	Sickle Cell
Alaafia Women's Corporation	<a href="http://www.strengthinsicklecell.com">www.strengthinsicklecell.com</a>	Sickle Cell
Alagille Syndrome Alliance	<a href="https://alagille.org/">https://alagille.org/</a>	Alagille Syndrome
All GOD's Children	n/a	General
All India Institute of Medical Sciences ( AIIMS), New Delhi, India	<a href="http://www.pedneuroaiims.org/index.html">http://www.pedneuroaiims.org/index.html</a>	SMA, DMD and Rett syndrome
All Things Kabuki	<a href="http://Allthingskabuki.org">Allthingskabuki.org</a>	Kabuki Syndrome
Alliance Algérienne contre les Maladies Rares	<a href="http://aamrdz.wix.com/rare">http://aamrdz.wix.com/rare</a>	All Rare Diseases
Alliance to Cure Cavernous Malformation (formerly Angioma Alliance)	<a href="https://www.AllianceToCure.org">https://www.AllianceToCure.org</a>	Cerebral Cavernous Malformation (aka Cavernoma, Cavernous Malformation, CCM)
Alstrom Syndrome International	<a href="http://www.alstrom.org">www.alstrom.org</a>	Alstrom Syndrome
Amyloidosis Research Consortium (ARC)	<a href="http://www.arci.org/">http://www.arci.org/</a>	Amyloidosis
ANGEL AID CARES [A Nonprofit Group Enriching Lives Inc]	<a href="https://www.angelaidcares.org/">https://www.angelaidcares.org/</a>	All Rare Diseases
Angelina Cask Neurological Research Foundation	<a href="https://acnrf.com">https://acnrf.com</a>	CASK Gene Mutations and Related Disorders

Angelman Syndrome Foundation	<a href="http://angelman.org">angelman.org</a>	Angelman Syndrome
Antonia Pauls Sickle Cell Disease Foundation - Uganda	<a href="https://antoniapaulsscdf.org">https://antoniapaulsscdf.org</a>	Sickle Cell Anemia
ARPKD/CHF Alliance	<a href="https://www.arpkdchf.org">https://www.arpkdchf.org</a>	Autosomal Recessive Polycystic Kidney Disease and Congenital Hepatic Fibrosis
As One Foundation	<a href="http://www.AsOneFoundation.org">http://www.AsOneFoundation.org</a>	Full Sickle Cell Hemoglobinopathy Spectrum
Association Aux Pas du Coeur	<a href="https://auxpasducoeur.life/">https://auxpasducoeur.life/</a>	Neuromuscular Diseases
ASXL Rare Research Endowment Foundation	<a href="http://www.arrefoundation.org">www.arrefoundation.org</a>	Asxl-Related Disorders (Bohring-Opitz Syndrome/Asxl1, Shashi-Pena Syndrome/Asxl2, Bainbridge-Ropers Syndrome/Asxl3)
Ataxia and me	<a href="http://www.ataxia-and-me.org">www.ataxia-and-me.org</a>	Ataxia, Associated Rare Disease And Movement Disorders
Auto-Brewery Syndrome Info and Research	<a href="http://www.autobrewery.info/">http://www.autobrewery.info/</a>	Auto-Brewery Syndrome
Autoimmune Registry Inc.	<a href="https://www.autoimmuneregistry.org/">https://www.autoimmuneregistry.org/</a>	All Autoimmune And Autoinflammatory Diseases
Autoinflammatory Alliance	<a href="https://autoinflammatory.org">https://autoinflammatory.org</a>	Autoinflammatory, CAPS, FMF, TRAPS, MKD/HIDS, SAVI, CANDLE/PRAAS, DIRA, PFAPA, Schnitzler Syndrome,
Avery's Hope	<a href="http://averys-hope.org">averys-hope.org</a>	Rare, Ultra Rare And Undiagnosed Pediatric Gi Diseases
Barth Syndrome Foundation	<a href="https://www.barthsyndrome.org">https://www.barthsyndrome.org</a>	Barth Syndrome
Beautiful You MRKH Foundation, Inc.	<a href="http://www.beautifulyoumrkh.org">www.beautifulyoumrkh.org</a>	Mayer-Rokitansky-Küster-Hauser Syndrome
Beck-Fahrner Syndrome Foundation	<a href="http://www.beckfahrner.org">www.beckfahrner.org</a>	Beck-Fahrner Syndrome
BFLS Incorporated	<a href="http://www.bflsinc.com">www.bflsinc.com</a>	BFLS, Börjeson-Forsman-Lehman Syndrome
BioMedVerse LLC	<a href="https://www.biomedversellc.com/">https://www.biomedversellc.com/</a>	Diseases of the Circulatory System ("Wolff-Parkinson White Syndrome")
Bleeding Disorders Alliance Illinois	<a href="http://www.bdai.org">www.bdai.org</a>	Inherited Bleeding Disorders
Boston International Turner Syndrome Summit	<a href="http://www.bitssummit.org">http://www.bitssummit.org</a>	Turner syndrome
Botswana Organisation for rare Diseases	<a href="http://www.bordis.org">http://www.bordis.org</a>	All Rare Diseases
Bow Foundation	<a href="https://gnao1.org/">https://gnao1.org/</a>	GNAO1 Related Neurodevelopmental Disorder
Breast Implant Victim Advocacy	<a href="https://m.facebook.com/breastimplantvictimadvocacy/">https://m.facebook.com/breastimplantvictimadvocacy/</a>	BIA-ALCL and Breast Implant Illness
Breathe Support Network	<a href="http://www.breathesupport.org">www.breathesupport.org</a>	Support Patients And Families Affected By Pulmonary Fibrosis
Bridging The Gap-Adult Sickle Cell Disease Foundation of Nevada	<a href="http://ascdfofnv.org">ascdfofnv.org</a>	Sickle Cell Disease
Broad Institute Rare Genomes Project	<a href="http://www.raregenomes.org">www.raregenomes.org</a>	Undiagnosed, Suspected Single Gene Disorder, and Their Family Members
Bubba's Light	<a href="https://www.bubbalight.com/">https://www.bubbalight.com/</a>	Peroxisomal Biogenesis Disease
CACNA1A Foundation	<a href="https://www.cacna1a.org/">https://www.cacna1a.org/</a>	Cacna1A-Related Diseases, Epilepsy, Ataxia (Episodic Ataxia Type 2, Spinocerebellar Ataxia Type 6, Congenital Ataxia), Hemiplegic Migraines, Nystagmus

Canadian Association of Pompe	<a href="https://www.pompecanada.com/">https://www.pompecanada.com/</a>	Pompe Disease
Canadian Society for Mucopolysaccharide & Related Diseases Inc.	<a href="https://www.mpssociety.ca/">https://www.mpssociety.ca/</a>	Mucopolysaccharidosis and Related Lysosomal Storage Disorders
Care-for-Rare America Inc	<a href="https://care-for-rare-america.org/">https://care-for-rare-america.org/</a>	Primary Immunodeficiencies (Pid), Very Early Onset Inflammatory Bowel Disease, And Other Rare Diseases Of The Blood, Bone Marrow, And Immune System.
Care4ASH1L	<a href="https://care4ash1l.com">https://care4ash1l.com</a>	Ash1L Related Disorders
Caring Hands Sarcoidosis Foundation	<a href="http://SarcoidNetwork.org">SarcoidNetwork.org</a>	Sarcoidosis
Castleman Disease Collaborative Network (CDCN); University of Pennsylvania	<a href="http://www.cdcn.org">www.cdcn.org</a>	Castleman Disease (various sub-types)
CDG Canada	<a href="https://canadacdg.com/">https://canadacdg.com/</a>	Congenital Disorders Of Glycosylation (Cdg)
CDG CARE	<a href="https://cdgcare.org/">https://cdgcare.org/</a>	Congenital Disorders of Glycosylation (CDG) and NGLY1 Deficiency
CDH International	<a href="http://www.cdhi.org">http://www.cdhi.org</a>	Congenital Diaphragmatic Hernia
CDKL5 Alliance	<a href="https://cdkl5alliance.org/">https://cdkl5alliance.org/</a>	CDKL5
CDKL5 Research Collaborative	<a href="https://www.cdkl5research.org">https://www.cdkl5research.org</a>	CDKL5 Deficiency Disorder
Center for Chronic Illness	<a href="http://www.thecenterforchronicillness.org">http://www.thecenterforchronicillness.org</a>	All Rare and Chronic Health Conditions
CF Get Loud	<a href="http://Cfgetloud.ca">Cfgetloud.ca</a>	Cystic Fibrosis
CFC International	<a href="https://www.cfcsyndrome.org/">https://www.cfcsyndrome.org/</a>	Cardio Facio Cutaneous Syndrome
CGD Association of America	<a href="http://CGDAA.org">CGDAA.org</a>	Chronic Granulomatous Disease
Charcot-Marie-Tooth Association	<a href="http://www.cmtausa.org">www.cmtausa.org</a>	Charcot-Marie-Tooth (Cmt) Disease
CHILD AND YOUTH CARE	<a href="http://www.cyc.org.zw">http://www.cyc.org.zw</a>	CAH, MPS
Children's Adaptability Network	<a href="http://Childrensadaptabilitynetwork.org">Childrensadaptabilitynetwork.org</a>	Any/All - Our Son Had Atrx Syndrome
Cholangiocarcinoma Foundation	<a href="http://cholangiocarcinoma.org">cholangiocarcinoma.org</a>	Cholangiocarcinoma
CHOPS Syndrome Global	<a href="http://Www.chopssyndrome.global.org">Www.chopssyndrome.global.org</a>	Mutation of the AFF4 Gene
Choroideremia Research Foundation	<a href="http://www.curechm.org">http://www.curechm.org</a>	Choroideremia
Chromosome 22 Central	<a href="http://www.c22c.org">http://www.c22c.org</a>	Disorders of Chromosome 22
Chyanna's Champions 4 Children (CC4C)	<a href="https://www.cc4c.org/">https://www.cc4c.org/</a>	Children & Families Living with Rare or Undiagnosed Diseases
CLOVES Syndrome Community	<a href="https://clovessyndrome.org/">https://clovessyndrome.org/</a>	Cloves Syndrome And Pik3Ca Related Overgrowth
CMTC-OVM	<a href="http://www.cmtc.nl/en">www.cmtc.nl/en</a>	CMTC and Other Vascular Malformations
Coalition to Cure CHD2	<a href="http://curechd2.org">http://curechd2.org</a>	CHD2-Related Neurodevelopmental Disorders
Cold Agglutinin Disease Foundation	<a href="http://coldagglutinin-disease.org">coldagglutinin-disease.org</a>	Cold Agglutinin Disease
Collaborative Research Advocacy for Vascular Anomalies Network (CaRAVAN)	<a href="http://www.caravannetwork.org">http://www.caravannetwork.org</a>	Vascular Anomalies
COMBINEDBrain Inc	<a href="https://combinedbrain.org">https://combinedbrain.org</a>	35 PAG That all Have Genetic, Neurological Disorders
Congenital Hyperinsulinism International	<a href="https://congenitalhi.org/">https://congenitalhi.org/</a>	Congenital Hyperinsulinism

Cookies4Cures	<a href="http://www.cookies4cures.com">www.cookies4cures.com</a>	Mcto, Sma, Veds, Pans, Batten, Slc6A1, Hae
Courageous Parents Network Inc	<a href="https://courageousparentsnetwork.org/">https://courageousparentsnetwork.org/</a>	Pediatric Rare Diseases/Disease Agnostic
CRMO Foundation	<a href="https://crmofoundation.org/">https://crmofoundation.org/</a>	Chronic Recurrent Multifocal Osteomyelitis, Chronic Bacterial Osteomyelitis
CSNK2A1 Foundation	<a href="http://www.csnk2a1foundation.org">www.csnk2a1foundation.org</a>	Okur-Chung Neurodevelopmental Syndrome
Cure ADSSL1	<a href="https://www.cure-adssl1.org/">https://www.cure-adssl1.org/</a>	ADSSL1/ADSS1 myopathy
Cure KCNH1 Foundation	<a href="https://www.curekcnh1.org/">https://www.curekcnh1.org/</a>	KCNH1-Related Disorders/Epileptic Encephalopathy, Temple-Baraiser Syndrome, Zimmermann-Laband Syndro
Cure Mito Foundation	<a href="https://www.curemito.org">https://www.curemito.org</a>	Leigh syndrome, Mitochondrial Diseases
Cure Mucopolysaccharidosis	<a href="http://www.curemucopolysaccharidosis.org">www.curemucopolysaccharidosis.org</a>	Mucopolysaccharidosis II Mucopolysaccharidosis II/III Mucopolysaccharidosis III and Sialidosis
Cure Rare Disease	<a href="https://www.curerareisease.org/">https://www.curerareisease.org/</a>	Duchenne Muscular Dystrophy, SCA3, LGMD 2g/2i/2b, ADSSL1
Cure SZT2	<a href="https://www.szt2.org/">https://www.szt2.org/</a>	Szt2
CureARS	<a href="http://www.curears.org">www.curears.org</a>	Mitochondrial Disease
CureCMT4J/Talia Duff Foundation	<a href="http://curecmt4j.org">curecmt4j.org</a>	CMT4J
CureDuchenne	<a href="https://www.cureduchenne.org">https://www.cureduchenne.org</a>	Duchenne Muscular Dystrophy and Becker Muscular Dystrophy
CureGRIN Foundation	<a href="http://curegrin.org">curegrin.org</a>	Monogenic GRI Disorders including GRIN1, GRIN2A, GRIN2B, GRIN2D, GRIA1, GRIA2, GRIA3, GRIA4, GRIK2.
CureSPG50	<a href="http://CureSPG50.org">CureSPG50.org</a>	SPG50
Cystic Fibrosis Research Institute	<a href="https://cfri.org/">https://cfri.org/</a>	Cystic Fibrosis
Cystinosis Research Network	<a href="http://www.cystinosis.org">www.cystinosis.org</a>	Cystinosis
DADA2 Foundation	<a href="http://dada2.org">dada2.org</a>	Deficiency of Adenosine Deaminase 2
Danny's Dose Alliance	<a href="http://www.dannysdose.com">www.dannysdose.com</a>	Als, Ald, Adrenal Insufficiency, Complex Diabetes, Bleeding Disorders, Pha, Ucd, Sickle Cell, Epilepsy, Mcadd And More
DDX3X Foundation	<a href="https://ddx3x.org">https://ddx3x.org</a>	DDX3X Syndrome
Dent Disease Foundation	<a href="http://www.dentdisease.org">www.dentdisease.org</a>	Rare Genetic Kidney Disease. Mutations in CLCN5 and OCRL Genes
Dreamsickle Kids Foundation, Inc	<a href="http://www.dreamsicklekids.org">www.dreamsicklekids.org</a>	Sickle Cell Disease And All Rare Diseases
DRESS Syndrome Foundation	<a href="http://www.dresssyndrome.org">http://www.dresssyndrome.org</a>	Drug Reaction with Eosinophilia and Systemic Symptoms
Dup15q Alliance	<a href="http://www.dup15q.org">http://www.dup15q.org</a>	Dup15q Syndrome
Dupuytren Research Group	<a href="http://dupuytren.org">http://dupuytren.org</a>	Dupuytren Disease
DYRK1A Syndrome US & International Association	<a href="http://www.dyrk1a.org">www.dyrk1a.org</a>	Dyrk1A Syndrome
Ehlers-Danlos Syndromes New Zealand	<a href="http://www.ehlers-danlos.org.nz">http://www.ehlers-danlos.org.nz</a>	Ehlers-Danlos Syndromes
EmesArmy	<a href="http://EmesArmy.org">Http://EmesArmy.org</a>	Childhood Blindness / Blind / Genetic Blindness / LCA
Endosalpingiosis Foundation INC	<a href="http://www.endofoundation.org">http://www.endofoundation.org</a>	Endosalpingiosis
Eric's Journey Foundation	<a href="http://ericjourney.org">ericjourney.org</a>	Hemophagocytic Lymphohistiocytosis (Hlh), Still'S Disease, All Rare Diseases
European Foundation for SATB2-Associated Syndrome (SATB2 Europe)	<a href="http://www.satb2europe.org">www.satb2europe.org</a>	SATB2-Associated Syndrome also referred as Glass Syndrome (Neurodevelopmental dDorder, Falls Under ID Disorders)
EveryLife Foundation for Rare	<a href="https://everylifefoundation.org">https://everylifefoundation.org</a>	All Rare Diseases

Diseases	<a href="#">g/</a>	
Expecting Health	<a href="https://expectinghealth.org/">https://expectinghealth.org/</a>	Pregnancy, Newborns and Genetics Serving Rare Disease and Newborn Screening Communities
Eyes on the Future	<a href="http://www.vickyseyes.org">www.vickyseyes.org</a>	Inherited Retina Dystrophy Linked To Gene Rdh12
Fabry Support & Information Group	<a href="http://www.fabry.org">www.fabry.org</a>	Fabry Disease
Factor-H	<a href="http://www.factor-h.org">http://www.factor-h.org</a>	Huntington's Disease
FAM177A1 RESEARCH FUND	<a href="http://www.fam177a1.org">http://www.fam177a1.org</a>	FAM177A1 Associated Disease
FamilieSCN2A Foundation	<a href="http://www.scn2a.org">www.scn2a.org</a>	Scn2A
Fanconi Anemia Research Fund	<a href="http://fanconi.org">http://fanconi.org</a>	Fanconi Anemia
FibroMadness	<a href="https://www.fibromadness.org/">https://www.fibromadness.org/</a>	Fibromyalgia, IBS, IC, Sleep Problems, Chronic Pain, Mental Health, CFS, Disability
Fibromuscular Dysplasia Society of America	<a href="http://www.fmdsa.org">www.fmdsa.org</a>	Fibromuscular Dysplasia (FMD)
Fibrous Dysplasia Foundation dba FD/MAS Alliance	<a href="https://fdmasalliance.org/">https://fdmasalliance.org/</a>	Fibrous Dysplasia, Mccune-Albright Syndrome
Fighting for Kaiden Foundation, Inc.	<a href="http://www.fightingforkaiden.org">www.fightingforkaiden.org</a>	Spinal Muscular Atrophy (SMA)
Foundation for Angelman Syndrome Therapeutics (FAST)	<a href="https://cureangelman.org/">https://cureangelman.org/</a>	Individuals with Angelman syndrome
Foundation for Angelman Syndrome Therapeutics Australia	<a href="http://www.cureangelman.org.au">www.cureangelman.org.au</a>	Angelman Syndrome
Foundation for Sarcoidosis Research	<a href="http://www.stopsarcodosis.org">www.stopsarcodosis.org</a>	Sarcoidosis
Foundation to Fight H-abc	<a href="http://h-abc.org">h-abc.org</a>	Hypomyelination with Atrophy of Basal Ganglia and Cerebellum (H-ABC)
FOXG1 Research Foundation	<a href="https://foxg1research.org/">https://foxg1research.org/</a>	FoxG1 Syndrome
Fundación RHYO	<a href="http://fundacionrhyo.org/">http://fundacionrhyo.org/</a>	Hipertensión Pulmonar, Fibrosis Pulmonar, Esclerosis Multiplique, Edema Macular
GACI Global	<a href="https://www.gaciglobal.org">https://www.gaciglobal.org</a>	GACI and ARHR2 caused by ENPP1 Deficiency, and GACI caused by ABCC6 Deficiency
Gaucher Community Alliance	<a href="http://www.gauchercommunity.org">www.gauchercommunity.org</a>	Gaucher
Genèsic Nonprofit Organization	<a href="http://www.genesicnonprofit.org">www.genesicnonprofit.org</a>	Sickle Cell Anemia
Genetic Epilepsy Team Australia	<a href="http://geneticpilepsyteam.com">http://geneticpilepsyteam.com</a>	Rare Epilepsy
Girls Chronically Rock	<a href="https://girlschronicallyrock.com/">https://girlschronicallyrock.com/</a>	Muscular Dystrophy
Global DARE Foundation	<a href="https://www.defeatadultrefsumeverywhere.org/">https://www.defeatadultrefsumeverywhere.org/</a>	Refsum Disease
Global Hydranencephaly Foundation	<a href="http://www.ghf.life">http://www.ghf.life</a>	Hydranencephaly
Global Liver Institute	<a href="http://globalliver.org">globalliver.org</a>	All Liver Diseases. Our Pediatric And Rare Team Would Be Interacting Member.
Glut1 Deficiency Foundation	<a href="http://www.G1DFoundation.org">www.G1DFoundation.org</a>	Glut1 Deficiency (Glucose Transporter Type 1 Deficiency Syndrome - Glut1DS, G1D)
Good Decisions Are The Best Medicine Workbook	<a href="http://www.goodmedicaldecisions.com">http://www.goodmedicaldecisions.com</a>	All Rare Diseases
GRIN2B Foundation	<a href="http://www.grin2b.org">www.grin2b.org</a>	Grin2B Related Neurodevelopmental Disorder
Hairy Cell Leukemia Foundation	<a href="https://www.hairycellleukemia.org">https://www.hairycellleukemia.org</a>	Hairy Cell Lukemia



HCU Network America	<a href="https://hcunetworkamerica.org">https://hcunetworkamerica.org</a>	Homocystinuria, Classical Homocystinuria (Cystathionine Beta Synthase), Cobalamin C, Cobalamin D, Cobalamin E, Cobalamin F, Cobalamin G, Cobalamin J, Cobalamin X, Severe Mthfr
Heart of a Giant Foundation	<a href="https://heartofagiant.org/">https://heartofagiant.org/</a>	Hypertension, Cardiomyopathies (DCM, HCM), Heart Diseases
Help Hope Live	<a href="http://www.helpohpelive.org">http://www.helpohpelive.org</a>	Transplant, Spinal Cord Injury, EDS, FOXP1, Cerebral Palsy, Cancer, Muscular Dystrophy, Multiple Sclerosis
Helping Hands for GAND	<a href="https://www.GATAD2B.org/">https://www.GATAD2B.org/</a>	GATAD2B-Associated Neurodevelopmental Disorder (GAND)
Hemophilia Foundation of Southern California	<a href="http://www.hemosowww.facebook.com/hemophiliasocalcal.org">www.hemosowww.facebook.com/hemophiliasocalcal.org</a>	Inherited/Genetic Bleeding Disorders
Hereditary Neuropathy Foundation	<a href="https://www.hnf-cure.org/">https://www.hnf-cure.org/</a>	Charcot Marie Tooth and Inherited Neuropathies
Hermansky-Pudlak Syndrome Network,	<a href="http://www.hpsnetwork.org">www.hpsnetwork.org</a>	Hermansky-Pudlak Syndrome
HESA	<a href="http://hesaonline.info">http://hesaonline.info</a>	Autoimmune Encephalitis
Hope Life International	<a href="http://hlilife.org">hlilife.org</a>	All Rare Diseases with Focus in Sickle Cell Disease
Hope Life Support & Empowerment Initiative	<a href="http://www.hlsein.org.ng/">www.hlsein.org.ng/</a>	All Rare Diseases with Focus in Sickle Cell Disease
Hope4Harper	<a href="http://www.hope4harper.com">http://www.hope4harper.com</a>	CDKL5
Hunter McAlpine	n/a	Hunter McAlpine
Hunters CMT4B3 Research Foundation Inc	<a href="http://cmt4b3research.org">http://cmt4b3research.org</a>	Charcot-Marie-Tooth Disease Type 4B3
Huntington's Disease Youth Organization (HDYO)	<a href="http://en.hdyo.org">en.hdyo.org</a>	Huntington's Disease and Juvenile HD
Hyper IgM Foundation	<a href="http://www.hyperigm.org">www.hyperigm.org</a>	Hyper IgM Syndrome
Hypersomnia Foundation	<a href="http://Hypersomniafoundation.org">http://Hypersomniafoundation.org</a>	Idiopathic Hypersomnia, Narcolepsy and Kleine-Levin Syndrome (KLS)
Hypertrophic Cardiomyopathy Association	<a href="http://4hcm.org">4hcm.org</a>	Hypertrophic Cardiomyopathy Spectrum Diseases
Hypertrophic Olivary Degeneration Association	<a href="http://www.HODAssoc.org">http://www.HODAssoc.org</a>	Hypertrophic Olivary Degeneration
HypoPARathyroidism Association, Inc	<a href="http://www.hypopara.org">www.hypopara.org</a>	Hypoparathyroidism, Surgical, Non Surgical- Genetic, Autoimmune, Idiopathic
I am in PAIN and yet I LAUGH	n/a	Pidd, Ehlers-Danlos Syndrome, Pots, Gastroparesis, & All Other Rare Diseases
iCAN KIDS DRC	n/a	Pediatric Patients
ICP Care	<a href="https://icpcare.org/">https://icpcare.org/</a>	Intrahepatic Cholestasis of Pregnancy
IDefine	<a href="http://idefine.org">http://idefine.org</a>	Kleefstra Syndrome
Illinois Spina Bifida Association	<a href="http://www.i-sba.org">www.i-sba.org</a>	Spina Bifida
INADcure Foundation	<a href="http://www.INADcure.org">www.INADcure.org</a>	Infantile Neuroaxonal Dystrophy
Inclusive Skating	<a href="http://www.inclusiveskating.org">http://www.inclusiveskating.org</a>	All Diseases
Indian Prader Willi Syndrome Association India	<a href="http://www.ipwsa.com/">http://www.ipwsa.com/</a>	Prader Willi Syndrome, Chromosome 15(Q11-Q13)
Indo US Organization for Rare Diseases (IndoUSrare)	<a href="https://www.indousrare.org/">https://www.indousrare.org/</a>	Disease Agnostic (All Rare Diseases)
Inspire Medical Communications, LCC	<a href="https://www.inspiremedicalcommunications.com/">https://www.inspiremedicalcommunications.com/</a>	Disease Agnostic (All Rare Diseases)
Intermountain PKU and Allied Disorders. Association	<a href="http://www.ipadutah.org">http://www.ipadutah.org</a>	PKU and Other Inborn Errors of Metabolism

International FOP Association	<a href="http://www.ifopa.org">http://www.ifopa.org</a>	Fibrodysplasia Ossificans Progressiva (FOP)
International Foundation for CDKL5 Research	<a href="http://www.cdkl5.com">www.cdkl5.com</a>	Cdkl5 Disorders
International Gaucher Alliance	<a href="http://www.gaucheralliance.org">www.gaucheralliance.org</a>	Gaucher Disease
International Pain Foundation	<a href="http://www.internationalpain.org">www.internationalpain.org</a>	Diseases Causing Chronic Pain
International Pemphigus Pemphigoid Foundation	<a href="https://www.pemphigus.org/">https://www.pemphigus.org/</a>	Pemphigus And Pemphigoid (Includes All Sub-Variants)
International Prader-Willi Syndrome Organisation	<a href="http://www.ipwso.org">www.ipwso.org</a>	Prader-Willi Syndrome
International WAGR Syndrome Association	<a href="http://www.wagr.org">http://www.wagr.org</a>	WAGR Syndrome, Aniridia, Wilms tumor
Jamal's Helping Hands	<a href="http://www.jamalshelpinghands.org">www.jamalshelpinghands.org</a>	Rare Disease
Jett Foundation	<a href="https://www.jettfoundation.org/">https://www.jettfoundation.org/</a>	Duchenne Muscular Dystrophy
Jordan's Guardian Angels	<a href="https://jordansguardianangels.org/">https://jordansguardianangels.org/</a>	Jordan's Syndrome (PPP2R5D, PPP2R1A, PPP2R5C)
Juju and Friends CLN2 Warrior Foundation	<a href="https://give.rarevillage.org/campaign/juju-and-friends-cln2-warrior-foundation/c386658">https://give.rarevillage.org/campaign/juju-and-friends-cln2-warrior-foundation/c386658</a>	CLN2 Batten Disease
Kabuki Syndrome Foundation	<a href="http://kabuksyndromefoundation.org">kabuksyndromefoundation.org</a>	Kabuki Syndrome
KBG Foundation	<a href="http://www.kbgfoundation.com">www.kbgfoundation.com</a>	Kbg Syndrome
KBG Syndrome Association	n/a	Kbg Syndrome- Ankrd11
KCNT1 Epilepsy Foundation	<a href="https://kcnt1epilepsy.org/">https://kcnt1epilepsy.org/</a>	Kcnt1 Related Epilepsy and Neurodevelopmental Disorders
KDM5C KARES Foundation	<a href="http://kdm5cfoundation.org">kdm5cfoundation.org</a>	KDM5C Related Genetic Disorders
KIF1A.ORG	<a href="http://www.KIF1A.org">www.KIF1A.org</a>	KIF1A Associated Neurological Disorder (KAND)
Koolen-de Vries Syndrome Foundation	<a href="http://www.kdvsfoundation.org">www.kdvsfoundation.org</a>	Koolen-De Vries Syndrome Foundation
Let Go Skate Co.	<a href="http://Letgoskateco.com">http://Letgoskateco.com</a>	Nail Patellar Syndrome
LGMD Awareness Foundation, Inc.	<a href="https://www.lgmd-info.org/">https://www.lgmd-info.org/</a>	30+ Subtypes Of Limb-Girdle Muscular Dystrophy (Lgmd)
Life and Family Foundation, VA	<a href="http://www.sicklecellva.org">www.sicklecellva.org</a>	Sickle Cell Disease
Life Branches NFP Inc	<a href="http://www.lifebranches.org">www.lifebranches.org</a>	All Rare Diseases
Lightning and Love Foundation	<a href="http://www.lightningandlove.org">www.lightningandlove.org</a>	Thap12 Recessive Genetic Disease
Littlest Tumor Foundation	<a href="https://littlesttumor.org">https://littlesttumor.org</a>	Neurofibromatosis
Living with Holt-Oram Syndrome	<a href="https://www.facebook.com/groups/livingwithholtoramssyndrome/?ref=share">https://www.facebook.com/groups/livingwithholtoramssyndrome/?ref=share</a>	Holt-Oram Syndrome
Louisiana Metabolic Disorders Coalition	<a href="http://louisianamdc.org">http://louisianamdc.org</a>	Metabolic Disorders-Amino Acid/Fatty Oxidation Disorders
Lymphangiomas & Gorham's Disease Alliance	<a href="https://www.lgdalliance.org/">https://www.lgdalliance.org/</a>	Complex Lymphatic Anomalies Including Generalized Lymphatic Anomaly, Gorham Stout Disease, Kaposiform Lymphangiomas And Central Conducting Lymphatic Anomaly
Lysosomal Storage Disorders Society - Pakistan	<a href="http://www.lsdpk.org">www.lsdpk.org</a>	All Lysosomal Storage Disorders
Lysosomal Storage Disorders Support Society	<a href="https://lsdssindia.org/">https://lsdssindia.org/</a>	Lysosomal Storage Disorders
Malan Syndrome Foundation	<a href="http://malansyndrome.org">malansyndrome.org</a>	Malan Syndrome
MarylandRARE	<a href="https://marylandrare.org/">https://marylandrare.org/</a>	Disease Agnostic (All Rare Diseases)

MCT8-AHDS Foundation	<a href="http://www.mct8.info">www.mct8.info</a>	MCT8 Deficiency also called Allan-Herndon-Dudley Syndrome
MECP2 Duplication Foundation	<a href="http://www.mecp2d.org">http://www.mecp2d.org</a>	MECP2 Duplication Syndrome
Meg's Miracles	<a href="http://www.megsmiracles.org">www.megsmiracles.org</a>	Stiff Person Syndrome (Pediatric And Adult Onset)
Melanin Children Matter Inc	<a href="http://melaninchildrenmatter.org">melaninchildrenmatter.org</a>	Sptlc2 Gene Mutation/ Pediatric Als
MEPAN Foundation	<a href="https://www.mepan.org">https://www.mepan.org</a>	MEPAN Syndrome
Mesothelioma Applied Research Foundation	<a href="http://www.curemeso.org">www.curemeso.org</a>	Mesothelioma
Miracle For Madison & Friends	<a href="http://www.miracleformadison.org/">http://www.miracleformadison.org/</a>	Spinal Muscular Atrophy
Mission: Cure	<a href="http://mission-cure.org">mission-cure.org</a>	Chronic And Recurrent Acute Pancreatitis
Mississippi Metabolics Foundation	<a href="https://www.msmetabolics.org/">https://www.msmetabolics.org/</a>	Genetic Metabolic Disorders/Inborn Errors Of Metabolism (Iem).
MLD Foundation	<a href="https://MLDfoundation.org">https://MLDfoundation.org</a>	Metachromatic Leukodystrophy
Moebius Syndrome Foundation	<a href="http://www.moebius syndrome.org">http://www.moebius syndrome.org</a>	Moebius Syndrome
Moonshots for Unicorns	<a href="https://moonshotsforunicorns.org/">https://moonshotsforunicorns.org/</a>	PGAP3-CDG, CDG, GPI Anchor Disorders, Single Gene Neurologic Disorders
Morquio Community	<a href="http://www.Morquiocommunity.org">www.Morquiocommunity.org</a>	Morquio Syndrome (MPS IV)
MSL3 Syndrome Foundation	<a href="http://msl3.org">http://msl3.org</a>	MSL3 Syndrome, Basilicata-Akhtar Syndrome
MTM-CNM Family Connection	<a href="http://www.mtm-cnm.org">www.mtm-cnm.org</a>	Myotubular Myopathy and Centronuclear Myopathy
My Faulty Gene	<a href="https://myfaultygene.org">https://myfaultygene.org</a>	Hereditary Cancers, Hereditary Heart Diseases
My Little Sunshine Foundation	<a href="http://www.mylittlesunshine.org">www.mylittlesunshine.org</a>	Infertility And Cancer
Myhre Syndrome Foundation	<a href="https://www.myhresyndrome.org/">https://www.myhresyndrome.org/</a>	Myhre Syndrome
Myositis Support and Understanding	<a href="https://understandingmyositis.org">https://understandingmyositis.org</a>	Idiopathic Inflammatory Myopathies - Polymyositis, Dermatomyositis, Inclusion Body Myositis, Immune Mediated Necrotizing Myopathy, Antisynthetase Syndrome
National Ataxia Foundation	<a href="http://ataxia.org">ataxia.org</a>	Ataxia
National Center of Hematology and Blood Transfusion	n/a	Anemia, Hemophilia, Sickle Cell Disease, Thalassemia Leukemia, Lymphoma, Myeloproliferative Diseasee
National Foundation for Ectodermal Dysplasias	<a href="https://www.nfed.org/">https://www.nfed.org/</a>	Ectodermal Dysplasias
National Fragile X Foundation	<a href="https://fragilex.org/">https://fragilex.org/</a>	Fragile X Syndrome; Fragile X-associated Tremor/Ataxia Syndrome; Fragile X-associate Primary Ovarian
National Gaucher Foundation of Canada	<a href="http://www.gauchercanada.ca">www.gauchercanada.ca</a>	Gaucher Disease
National Organization for Disorders of the Corpus Callosum	<a href="http://nod.org">nod.org</a>	Agenesis of the Corpus Callosum, Hypoplasia of the Corpus Callosum, Disorders of the Corpus Callosum
National Organization of African Americans with Cystic Fibrosis	<a href="https://noaacf.org/">https://noaacf.org/</a>	Cystic Fibrosis
National PKU Alliance	<a href="https://www.npkua.org">https://www.npkua.org</a>	National PKU Alliance
National PKU News	<a href="https://pkunews.org">https://pkunews.org</a>	PKU and Similar Inborn Errors of Metabolism



NBIA Disorders Association	<a href="http://www.NBIAdisorders.org">www.NBIAdisorders.org</a>	Neurodegeneration With Brain Iron Accumulation (Nbia) - 10 Different Disorders Under Our Umbrella.
NCBRS Worldwide Foundation	<a href="http://www.ncbrs.com">http://www.ncbrs.com</a>	Nicolaides-Baraitser Syndrome
Neuroendocrine Cancer Awareness Network Inc	<a href="http://netcancerawareness.org">netcancerawareness.org</a>	Neuroendocrine, Carcinoid, Carcinoid Syndrome
Neuromuscular Disease Foundation	<a href="http://www.CureGNEM.org">www.CureGNEM.org</a>	Gne Myopathy
Nevus Outreach	<a href="http://www.nevus.org">http://www.nevus.org</a>	Congenital Melanocytic Nevi and Related Disorders Including Neurocutaneous Melanosis and Melanoma
New York City Hemophilia Chapter	<a href="http://www.nyhemophilia.org">www.nyhemophilia.org</a>	Hemophilia
New Zealand Amyloidosis Patients Association	<a href="http://www.amyloidosis.co.nz">www.amyloidosis.co.nz</a>	Amyloidosis
New Zealand Pompe Network	<a href="https://www.nzpompe.network/">https://www.nzpompe.network/</a>	Pompe Disease
NF2 BioSolutions	<a href="https://nf2biosolutions.org/">https://nf2biosolutions.org/</a>	Neurofibromatosis Type 2
NGO «Rare Diseases of Ukraine»	<a href="https://www.facebook.com/orphandisua">https://www.facebook.com/orphandisua</a>	Orphan Diseases
NGO Association of Patients with Pulmonary Hypertension	<a href="http://pha.org.ua">pha.org.ua</a>	Pulmonary Hypertension
Our Odyssey	<a href="https://ourodyssey.org/">https://ourodyssey.org/</a>	Disease Agnostic (All Rare Diseases)
Pan African Vision for the Environment(PAVE)	n/a	All Rare Diseases in Nigeria
Parent it Forward Corporation	<a href="https://parentitforward.org/">https://parentitforward.org/</a>	Children with a Rare or Not Rare Diseases
Parent Project Muscular Dystrophy	<a href="http://www.ppmindia.org">www.ppmindia.org</a>	Duchenne Muscular Dystrophy
Pathways for Rare and Orphan Studies	<a href="http://www.prosfoundation.org">www.prosfoundation.org</a>	Rare and Undiagnosed Diseases
Pathways To Trust	<a href="http://www.pathwaystotrust.org">www.pathwaystotrust.org</a>	Sickle Cell Disease; Ehlers-Danlos Syndrome
Patient Advocate Foundation	<a href="http://www.patientadvocate.org">www.patientadvocate.org</a>	Any Chronic, Life-Threatening Or Debilitating Disease
PBC Foundation	<a href="http://www.pbcfoundation.org.uk">www.pbcfoundation.org.uk</a>	Primary Biliary Cholangitis
Peer Medical Foundation	<a href="https://peermedfoundation.org/">https://peermedfoundation.org/</a>	All Disease or Genetic Conditions
People With Empathy	<a href="http://www.peoplewithempathy.org">www.peoplewithempathy.org</a>	Rare disease/Autoimmune (general)
Petronille Healthy Society	<a href="https://www.petronillehealthy.society.org/">https://www.petronillehealthy.society.org/</a>	Blood Diseases and Disorders
Platelet Disorder Support Association	<a href="https://pdsa.org/">https://pdsa.org/</a>	Immune Thrombocytopenia (ITP)
PO"UAP PKU "Special children"	<a href="http://www.detipku.org.ua/">http://www.detipku.org.ua/</a>	Phenylketonuria
PPP3CA	<a href="http://www.ppp3ca.org">www.ppp3ca.org</a>	Mutation On Ppp3Ca Gene
Prader-Willi Syndrome Association USA	<a href="http://www.pwsausa.org">http://www.pwsausa.org</a>	Prader-Willi Syndrome
PRISMS, Inc.	<a href="http://www.prisms.org">www.prisms.org</a>	Smith-Magenis Syndrome
Progressive Familial Intrahepatic Cholestasis Advocacy and Resource Network	<a href="http://www.pfic.org">http://www.pfic.org</a>	PFIC and PFIC Related Diseases
Project 8p Foundation	<a href="https://project8p.org">https://project8p.org</a>	Chromosome 8p Disorder
Project Alive	<a href="https://projectalive.org/">https://projectalive.org/</a>	Mucopolysaccharidosis (MPS II)
Project Clio	<a href="http://www.projectclio.org">http://www.projectclio.org</a>	Rare Immune-Mediated Disease (Including Rasmussen's Encephalitis (RE), Goodpasture's, SCIDs, Wiskott-Aldrich Syndrome, Ataxia Telangiectasia, DiGeorge

		Syndrome, Immuno-Osseous Dysplasias) as well as MS and T1D
Project FAVA	<a href="https://www.projectfava.org">https://www.projectfava.org</a>	Fibro-Adipose Vascular Anomalies (Fava)
Project Sebastian	<a href="http://www.projectsebastian.org">http://www.projectsebastian.org</a>	Primarily Batten
PVNH Support & Awareness	<a href="http://www.PVNHsupport.com">www.PVNHsupport.com</a>	X-Linked Periventricular Nodular Heterotopia, Grey Matter Heterotopia, Subcortical Heterotopia, Subcortical Band heterotopia
Pyruvate Kinase Deficiency Foundation	<a href="http://pkdf.org">pkdf.org</a>	Pyruvate Kinase Deficiency
Raising Hope International Friends	<a href="http://www.raisinghopeinternational.org">www.raisinghopeinternational.org</a>	Sickle Cell Disease
Rare Disease Ghana Initiative	<a href="http://www.rarediseaseghana.org">www.rarediseaseghana.org</a>	All Rare Diseases
Rare Disease Male Mental Health Support Group	<a href="https://www.facebook.com/groups/991558431661517/">https://www.facebook.com/groups/991558431661517/</a>	All Rare Diseases
Rare Diseases South Africa NPC	<a href="http://www.rarediseases.co.za">www.rarediseases.co.za</a>	All Rare Conditions
Rare Disorders Kenya	<a href="http://www.rarediseasekenya.org">www.rarediseasekenya.org</a>	All Rare Diseases
Rare Families Canada	n/a	Rare And Chronic Diseases (Disease Agnostic)
Rare Village Foundation	<a href="https://rarevillage.org">https://rarevillage.org</a>	All Rare Disease
RareKC	<a href="http://www.rarekc.org">www.rarekc.org</a>	All Rare Diseases in The Region
RASopathies Network	<a href="https://RASopathiesNet.org">https://RASopathiesNet.org</a>	RASopathies, Namely CFC, Costello and the Noonan Syndromes
Raymond A. Wood Foundation	<a href="https://www.rawoodfoundation.org/">https://www.rawoodfoundation.org/</a>	Craniopharyngioma
Recurrent Respiratory Papillomatosis Foundation	<a href="http://www.rrpf.org">www.rrpf.org</a>	Recurrent Respiratory Papillomatosis, Laryngeal Papillomatosis, Pulmonary Rrp, Tracheal Papillomatosis, Lung Cancer
Remember The Girls	<a href="http://rememberthegirls.org">rememberthegirls.org</a>	Carriers of Rare X-linked Diseases
Ryan's Challenge	n/a	Vascular Ehlers-Danlos Syndrome
SALUS	n/a	Rare Cancers (Desmoid, Ewings Sarcoma, Angioimmunoblastic Tcell, Others); Ipf
Sappani Foundation	<a href="https://sappanifoundation.com/">https://sappanifoundation.com/</a>	Rare Diseases And Congenital Disorders Of Glycosylation (Cdg)
SATB2 Gene Foundation	<a href="http://www.satb2gene.org">www.satb2gene.org</a>	Satb2-Associated Syndrome (Aka Glass Syndrome)
SCN2A Asia Pacific	<a href="http://www.scn2aaustralia.org">www.scn2aaustralia.org</a>	Scn2A - Autism Or Epilepsy
SCN2A GEORGIAN ASSOCIATION	n/a	Scn2A Gene
SETBP1 Society	<a href="https://setbp1.org">https://setbp1.org</a>	SETBP1 Haploinsufficiency Disorder, SETBP1-related Disorder
Shwachman-Diamond Syndrome Alliance Inc	<a href="http://www.SDSAlliance.org">www.SDSAlliance.org</a>	Shwachman-Diamond Syndrome
Sickle Cell 101	<a href="https://www.sc101.org/">https://www.sc101.org/</a>	Sickle Cell Disease
SICKLE CELL AWARENESS FOUNDATION CORP INT	<a href="http://www.scafc.org">www.scafc.org</a>	Sickle Cell Disease/Sickle Cell Trait
Sickle Cell Coalition of Maryland	n/a	Dreamsickle
Sickle Cell Foundation of MN	<a href="http://www.sicklecellmn.org">www.sicklecellmn.org</a>	Sickle Cell Disease
Sickle Cell Reproductive Health Education Directive	<a href="http://www.sicklecellred.org">http://www.sicklecellred.org</a>	Sickle Cell and Sickle Cell Trait
Siegel Rare Neuroimmune Association	<a href="https://wearesrna.org/">https://wearesrna.org/</a>	Rare Neuroimmune Disorders Including: Acute Disseminated Encephalomyelitis (Adem), Acute Flaccid Myelitis (Afm), Mog Antibody Disease (Mogad), Neuromyelitis

		Optica Spectrum Disorder (Nmosd), Optic Neuritis (On) And Transverse Myelitis (Tm)
Sisters' Hope Foundation	<a href="http://www.sistershopefoundation.org">http://www.sistershopefoundation.org</a>	ALSP, CSF1R Related Leukoencephalopathy
SLC6A1 Connect	<a href="http://slc6a1connect.org">http://slc6a1connect.org</a>	SLC6A1 Gene Mutation and Related Disorders
Soft Bones, Inc., The US Hypophosphatasia Foundation	<a href="http://www.softbones.org">www.softbones.org</a>	Hypophosphatasia
Sophie's Hope Foundation, Inc	<a href="http://www.sophieshopefoundation.org">www.sophieshopefoundation.org</a>	Glycogen Storage Disease Type 1B
Special Education Teaching and Learning Inc.	<a href="https://teachrare.org">https://teachrare.org</a>	Aromatic L-Amino Decarboxylase Deficiency
Stronger Than Sarcoidosis	<a href="https://www.strongerthansarcoidosis.org/">https://www.strongerthansarcoidosis.org/</a>	Sarcoidosis
STXBP1 e.V.	<a href="https://stxbp1-ev.de">https://stxbp1-ev.de</a>	STXBP1 Encephalopathy and Disorder
STXBP1 Foundation	<a href="https://www.stxbp1disorders.org/">https://www.stxbp1disorders.org/</a>	STXBP1 genetic disorders
Super T's Mast Cell Foundation	<a href="http://supertmastcell.org">http://supertmastcell.org</a>	Mast Cell Disease/Mastocytosis
Supporters of Families with Sickle Cell Disease, Inc	<a href="http://www.sicklecelloklahoma.org">http://www.sicklecelloklahoma.org</a>	Sickle Cell Disease and its Inherited Disorders and Traits
Syndromes Without A Name (SWAN) Australia	<a href="https://swanaus.org.au/">https://swanaus.org.au/</a>	Undiagnosed and Rare Genetic Conditions
SynGAP Research Fund	<a href="https://www.syngapresearchfund.org">https://www.syngapresearchfund.org</a>	SYNGAP1
T.E.A.M. 4 Travis (Together Ending Asplenia Mortality)	<a href="http://www.team4travis.org">www.team4travis.org</a>	Isolated Congenital Asplenia
TANGO2 Research Foundation	<a href="http://tango2research.org">tango2research.org</a>	TANGO2-Related Disorder
Tatton Brown Rahman Syndrome Community	<a href="https://tbrsyndrome.org">https://tbrsyndrome.org</a>	Tatton Brown Rahman Syndrome
Team Telomere	<a href="http://teamtelomere.org">http://teamtelomere.org</a>	Telomere Biology Disorders
Team Titin	<a href="https://titinmyopathy.com/">https://titinmyopathy.com/</a>	Titin Related Muscle and Heart Disorders
TED Community Foundation	<a href="https://tedcommunity.org">https://tedcommunity.org</a>	Thyroid Eye Disease (TED)
Teddington Trust	<a href="http://www.teddingtontrust.com">http://www.teddingtontrust.com</a>	Xeroderma Pigmentosum
TESS Research Foundation	<a href="http://tessresearch.org">tessresearch.org</a>	SLC13A5 Epilepsy, a Citrate Transporter Disorder
The Akari Foundation	<a href="http://theakarifoundation.org">theakarifoundation.org</a>	Duchenne Muscular Dystrophy
The Allo Hope Foundation	<a href="http://www.allohopefoundation.org">www.allohopefoundation.org</a>	Maternal Alloimmunization and HDFN (Hemolytic Disease of the Fetus and Newborn)
The Assistance Fund	<a href="http://www.assistfund.org">http://www.assistfund.org</a>	Multiple Sclerosis, Cystic Fibrosis, Advanced Breast Cancer, Parkinson's
The Bonnell Foundation: Living with Cystic Fibrosis	<a href="https://thebonnellfoundation.org">https://thebonnellfoundation.org</a>	Cystic Fibrosis
The CASK Gene Foundation	<a href="https://www.caskgene.org/">https://www.caskgene.org/</a>	CASK Related Gene Disorders
The Champ Foundation	<a href="https://www.thechampfoundation.org/">https://www.thechampfoundation.org/</a>	Single Large-scale Mitochondrial Deletion Syndromes (SLSMDS), like Pearson Syndrome
The Chandler Project	<a href="https://thechandlerproject.org/">https://thechandlerproject.org/</a>	Achondroplasia, Dwarfism, Skeletal Dysplasias
The Children's Rare Disorders Fund	<a href="http://www.thecrdfund.org">http://www.thecrdfund.org</a>	Rare Genetic Disorders
The Cute Syndrome Foundation	<a href="https://www.thecutesyndrome.com/">https://www.thecutesyndrome.com/</a>	SCN8A Disorders
The Dynamite Foundation Inc	<a href="http://ifightlikedynamite.org">http://ifightlikedynamite.org</a>	Histiocytosis: LCH, HLH, ECD, RDD, JXG

The E.WE Foundation	<a href="http://www.theewefoundation.org">www.theewefoundation.org</a>	Edwards Syndrome, Trisomy 18
The Ehlers-Danlos Society	<a href="https://www.ehlers-danlos.com/">https://www.ehlers-danlos.com/</a>	Eds And Hsd
The Global Foundation for Peroxisomal Disorders	<a href="http://www.thegfpd.org">www.thegfpd.org</a>	Peroxisomal Disorders In The Zellweger Spectrum And The Related Single Enzyme Protein Deficiencies
The Jansen de Vries Syndrome Foundation	<a href="https://jansen-devries.org/">https://jansen-devries.org/</a>	Jansen de Vries Syndrome
The Jansen's Foundation	<a href="https://www.thejansensfoundation.org/">https://www.thejansensfoundation.org/</a>	Jansen's Metaphyseal Chondrodysplasia
The JDS Foundation	<a href="https://www.facebook.com/groups/506130270955118/">https://www.facebook.com/groups/506130270955118/</a>	Primary Mediastinal Germ Cell Tumors
The KCNC1 Foundation	<a href="http://www.kcnc1.org">http://www.kcnc1.org</a>	KCNC1-Related Disorders: Epilepsy, NDD, Autism, ID, DD
The Marfan Foundation	<a href="http://Marfan.org">http://Marfan.org</a>	Marfan Syndrome, Loeys-Dietz Syndrome, Vascular Ehlers-Danlos Syndrome
The Mast Cell Disease Society	<a href="http://www.tmsforacure.org">www.tmsforacure.org</a>	Mastocytosis and Variants, Mast Cell Activation Syndrome, Hereditary Alpha Trypsasemia
The Menkes Foundation	<a href="http://www.themenkesfoundation.org">http://www.themenkesfoundation.org</a>	Menkes Disease
The MOG Project	<a href="https://mogproject.org/">https://mogproject.org/</a>	Myelin Oligodendrocyte Glycoprotein Antibody Disease (MOGAD)
The PURA Syndrome Foundation	<a href="http://purasyndrome.org">purasyndrome.org</a>	Genetic Conditions
The Scheuermann's Disease Fund	<a href="http://www.sdfund.org">www.sdfund.org</a>	Scheuermann's Disease
The SHANK2 Foundation	<a href="http://shank2.org">shank2.org</a>	Shank2 Disorder
The Stiff Person Syndrome Research Foundation	<a href="https://stiffperson.org">https://stiffperson.org</a>	Stiff Person Syndrome
The TBCK Foundation	<a href="http://www.tbckfoundation.com">www.tbckfoundation.com</a>	Tbck Syndrome
The XLH Network, Inc.	<a href="http://xlhnetwork.org">xlhnetwork.org</a>	X-Linked Hypophosphatemia
ThinkGenetic Foundation	<a href="http://thinkgenetic.org">http://thinkgenetic.org</a>	All Rare Diseases
Thrive with Pyruvate Kinase Deficiency Organization	<a href="https://thrivewithpkd.org/">https://thrivewithpkd.org/</a>	Pyruvate Kinase Deficiency
Timothy Syndrome Alliance	<a href="http://www.timothysyndrome.org">www.timothysyndrome.org</a>	Cacna1C-Related Disorders, Timothy Syndrome, Longqt8
Tin Soldiers Global FOP Patient Search	<a href="http://www.tinsoldiers.org">www.tinsoldiers.org</a>	Fibrodysplasia Ossificans Progressiva (FOP) and Broader Musculoskeletal Conditions
To Cure a Rose Foundation	<a href="http://tocurearose.org">tocurearose.org</a>	HNRNPH2 and Other Similar Monogenic Rare Diseases
Transplant Unwrapped	<a href="http://www.transplantunwrapped.org">www.transplantunwrapped.org</a>	Intestinal Failure, Short Bowel SYndrome, HPN Nutrition, Gastroparesis, CIPO
TSC Alliance	<a href="https://www.tscalliance.org/">https://www.tscalliance.org/</a>	Tuberous Sclerosis Complex
Turner Syndrome Global Alliance	<a href="http://tsgalliance.org/">http://tsgalliance.org/</a>	Turner Syndrome (TS)
Undiagnosed Diseases Network Foundation (UDNF)	<a href="http://UDNF.org">http://UDNF.org</a>	Undiagnosed / Misdiagnosed/New Ultra Rare Diseases
Unfixed	<a href="http://www.unfixedmedia.com">http://www.unfixedmedia.com</a>	All Rare Diseases
United For Scleroderma	n/a	Scleroderma
United Mitochondrial Disease Foundation	<a href="http://www.umdf.org">www.umdf.org</a>	Mitochondrial Disorders
United MSD Foundation	<a href="https://curemsd.org/">https://curemsd.org/</a>	Multiple Sulfatase Deficiency
United Porphyrias Association	<a href="http://www.porphyrria.org">http://www.porphyrria.org</a>	Porphyria
Upequity	<a href="http://www.upequity.org">http://www.upequity.org</a>	All Rare and Chronic Health Conditions

<b>Uplifting Athletes Inc.</b>	<a href="http://www.upliftingathletes.org">www.upliftingathletes.org</a>	<b>Disease Agnostic (All Rare Diseases)</b>
<b>Uriel E. Owens Sickle Cell Disease Association of the Midwest</b>	<a href="http://www.sicklecellmidwest.org">www.sicklecellmidwest.org</a>	<b>Sickle Cell Disease and Sickle Cell Trait</b>
<b>Usher 1F Collaborative</b>	<a href="https://www.usher1f.org">https://www.usher1f.org</a>	<b>Usher Syndrome Type 1F</b>
<b>Usher Syndrome Coalition</b>	<a href="http://www.usher-syndrome.org">www.usher-syndrome.org</a>	<b>Usher Syndrome</b>
<b>VICKtorious (formerly Rareability)</b>	<a href="http://www.vicktorious.org">www.vicktorious.org</a>	<b>Autoimmune Conditions - Primary Immunocompromised</b>
<b>Vidas Raras Institute</b>	<a href="http://www.vidasraras.org.br">http://www.vidasraras.org.br</a>	<b>Rare Diseases</b>
<b>Virginia Sickle Cell Network</b>	<a href="http://www.vasicklecellnetwork.org">http://www.vasicklecellnetwork.org</a>	<b>Sickle Cell</b>
<b>Vision for Tomorrow Foundation</b>	<a href="https://visionfortomorrow.org">https://visionfortomorrow.org</a>	<b>Aniridia, Albinism</b>
<b>wAIHA Warriors</b>	<a href="http://waihawarriors.org">waihawarriors.org</a>	<b>Warm Autoimmune Hemolytic Anemia</b>
<b>We are Familial ALS</b>	<a href="https://www.facebook.com/familialals/">https://www.facebook.com/familialals/</a>	<b>Pre-Manifest Genetic ALS</b>
<b>Wilhelm Foundation</b>	<a href="http://www.wilhelmfoundation.org">www.wilhelmfoundation.org</a>	<b>Undiagnosed Diseases</b>
<b>William E. Proudford Sickle Cell Fund Inc.</b>	<a href="http://wepsicklecell.org">wepsicklecell.org</a>	<b>Sickle Cell Disease And Trait</b>
<b>WonderFIL Smiles</b>	<a href="https://wonderfilsmiles.com/">https://wonderfilsmiles.com/</a>	<b>The PROS (PIK3CA Related Overgrowth Spectrum) Condition FIL (Facial Infiltrating Lipomatosis)</b>
<b>Wylder Nation Foundation</b>	<a href="http://WylderNation.org">WylderNation.org</a>	<b>Niemann-Pick Disease/Acid Sphingomyelinase Deficiency (ASMD)</b>
<b>YBRP, Inc</b>	<a href="http://ybrp.org">http://ybrp.org</a>	<b>HNRNP2 Related Disorder</b>
<b>Youngtimers, Inc.</b>	<a href="http://youngtimers.org">youngtimers.org</a>	<b>Early Onset Familial Alzheimer's Disease</b>
<b>Youth and Women for Opportunities Uganda-YWOU</b>	<a href="https://www.facebook.com/YWOUg/">https://www.facebook.com/YWOUg/</a>	<b>All Rare Diseases, Neuromuscular, Lysosomal Storage Disorders, Inherited Metabolic Disorders</b>
<b>Zebra CARE Initiative</b>	<a href="https://zebra-care.org/">https://zebra-care.org/</a>	<b>Ehlers Danlos Syndrome</b>
<b>Zoe's Story</b>	<a href="https://zoestory.org/">https://zoestory.org/</a> <a href="https://zoestory.org/">https://zoestory.org/</a>	<b>CRMO and All Children Facing Serious Rare Illnesses</b>
<b>ZTTK SON-Shine Foundation</b>	<a href="http://www.zttksonshinefoundation.org">http://www.zttksonshinefoundation.org</a>	<b>ZTTK Syndrome</b>

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