



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

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

Care-for-Rare America Inc	https://care-for-rare-america.org/	Primary Immunodeficiencies (Pid), Very Early Onset Inflammatory Bowel Disease, And Other Rare Diseases Of The Blood, Bone Marrow, And Immune System.
Care4ASH1L	https://care4ash1l.com	Ash1L Related Disorders
Caring Hands Sarcoidosis Foundation	SarcoidNetwork.org	Sarcoidosis
Castleman Disease Collaborative Network (CDCN); University of Pennsylvania	www.cdcn.org	Castleman Disease (various sub-types)
CDG Canada	https://canadacdg.com/	Congenital Disorders Of Glycosylation (Cdg)
CDG CARE	https://cdgcare.org/	Congenital Disorders of Glycosylation (CDG) and NGLY1 Deficiency
CDH International	http://www.cdhi.org	Congenital Diaphragmatic Hernia
CDKL5 Alliance	https://cdkl5alliance.org/	CDKL5
CDKL5 Research Collaborative	https://www.cdkl5research.org	CDKL5 Deficiency Disorder
Center for Chronic Illness	http://www.thecenterforchronicillness.org	All Rare and Chronic Health Conditions
CF Get Loud	Cfgetloud.ca	Cystic Fibrosis
CFC International	https://www.cfcsyndrome.org/	Cardio Facio Cutaneous Syndrome
CGD Association of America	CGDAA.org	Chronic Granulomatous Disease
Charcot-Marie-Tooth Association	www.cmtausa.org	Charcot-Marie-Tooth (Cmt) Disease
CHILD AND YOUTH CARE	http://www.cyc.org.zw	CAH, MPS
Children's Adaptability Network	Childrensadaptabilitynetwork.org	Any/All - Our Son Had Atrx Syndrome
Cholangiocarcinoma Foundation	cholangiocarcinoma.org	Cholangiocarcinoma
CHOPS Syndrome Global	Www.chopssyndrome.global.org	Mutation of the AFF4 Gene
Choroideremia Research Foundation	http://www.curechm.org	Choroideremia
Chromosome 22 Central	http://www.c22c.org	Disorders of Chromosome 22
Chyanna's Champions 4 Children (CC4C)	https://www.cc4c.org/	Children & Families Living with Rare or Undiagnosed Diseases
CLOVES Syndrome Community	https://clovessyndrome.org/	Cloves Syndrome And Pik3Ca Related Overgrowth
CMTC-OVM	www.cmtc.nl/en	CMTC and Other Vascular Malformations
Coalition to Cure CHD2	http://curechd2.org	CHD2-Related Neurodevelopmental Disorders
Cold Agglutinin Disease Foundation	coldagglutinin.disease.org	Cold Agglutinin Disease
Collaborative Research Advocacy for Vascular Anomalies Network (CaRAVAN)	http://www.caravannetwork.org	Vascular Anomalies
COMBINEDBrain Inc	https://combinedbrain.org	35 PAG That all Have Genetic, Neurological Disorders
Congenital Hyperinsulinism International	https://congenitalhi.org/	Congenital Hyperinsulinism
Cookies4Cures	www.cookies4cures.com	Mcto, Sma, Veds, Pans, Batten, Slc6A1, Hae
Courageous Parents Network Inc	https://courageousparentsnetwork.org/	Pediatric Rare Diseases/Disease Agnostic
CRMO Foundation	https://crmofoundation.org/	Chronic Recurrent Multifocal Osteomyelitis, Chronic Bacterial Osteomyelitis

CSNK2A1 Foundation	www.csnk2a1foundation.org	Okur-Chung Neurodevelopmental Syndrome
Cure KCNH1 Foundation	https://www.curekcnh1.org/	KCNH1-Related Disorders/Epileptic Encephalopathy, Temple-Baraiser Syndrome, Zimmermann-Laband Syndro
Cure Mito Foundation	https://www.curemito.org	Leigh syndrome, Mitochondrial Diseases
Cure Mucopolidosis	www.curemucopolidosis.org	Mucopolidosis II Mucopolidosis II/III Mucopolidosis III and Sialidosis
Cure Rare Disease	https://www.curerareisease.org/	Duchenne Muscular Dystrophy, SCA3, LGMD 2g/2i/2b, ADSSL1
Cure SZT2	https://www.szt2.org/	Szt2
CureARS	www.curears.org	Mitochondrial Disease
CureCMT4J/Talia Duff Foundation	curecmt4j.org	CMT4J
CureDuchenne	https://www.cureduchenne.org	Duchenne Muscular Dystrophy and Becker Muscular Dystrophy
CureGRIN Foundation	curegrin.org	Monogenic GRI Disorders including GRIN1, GRIN2A, GRIN2B, GRIN2D, GRIA1, GRIA2, GRIA3, GRIA4, GRIK2.
CureSPG50	CureSPG50.org	SPG50
Cystic Fibrosis Research Institute	https://cfri.org/	Cystic Fibrosis
Cystinosis Research Network	www.cystinosis.org	Cystinosis
DADA2 Foundation	dada2.org	Deficiency of Adenosine Deaminase 2
Danny's Dose Alliance	www.dannysdose.com	Als, Ald, Adrenal Insufficiency, Complex Diabetes, Bleeding Disorders, Pha, Ucd, Sickle Cell, Epilepsy, Mcadd And More
DDX3X Foundation	https://ddx3x.org	DDX3X Syndrome
Dent Disease Foundation	www.dentdisease.org	Rare Genetic Kidney Disease. Mutations in CLCN5 and OCRL Genes
Dreamsickle Kids Foundation, Inc	www.dreamsicklekids.org	Sickle Cell Disease And All Rare Diseases
DRESS Syndrome Foundation	http://www.dresssyndrome.org	Drug Reaction with Eosinophilia and Systemic Symptoms
Dup15q Alliance	http://www.dup15q.org	Dup15q Syndrome
Dupuytren Research Group	http://dupuytren.org	Dupuytren Disease
DYRK1A Syndrome US & International Association	www.dyrk1a.org	Dyrk1A Syndrome
Ehlers-Danlos Syndromes New Zealand	http://www.ehlers-danlos.org.nz	Ehlers-Danlos Syndromes
EmesArmy	Http://EmesArmy.org	Childhood Blindness / Blind / Genetic Blindness / LCA
Endosalpingiosis Foundation INC	http://www.endofoundation.org	Endosalpingiosis
Eric's Journey Foundation	ericsjourney.org	Hemophagocytic Lymphohistiocytosis (Hlh), Still'S Disease, All Rare Diseases
European Foundation for SATB2-Associated Syndrome (SATB2 Europe)	www.satb2europe.org	SATB2-Associated Syndrome also referred as Glass Syndrome (Nevrodevelopmental dDsorder, Falls Under ID Disorders)
EveryLife Foundation for Rare Diseases	https://everylifefoundation.org/	All Rare Diseases
Expecting Health	https://expectinghealth.org/	Pregnancy, Newborns and Genetics Serving Rare Disease and Newborn Screening Communities
Eyes on the Future	www.vickyseyes.org	Inherited Retina Dystrophy Linked To Gene Rdh12

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

Help Hope Live	http://www.helphopelive.org	Transplant, Spinal Cord Injury, EDS, FOXP1, Cerebral Palsy, Cancer, Muscular Dystrophy, Multiple Sclerosis
Helping Hands for GAND	https://www.GATAD2B.org/	GATAD2B-Associated Neurodevelopmental Disorder (GAND)
Hemophilia Foundation of Southern California	www.hemosowww.facebook.com/hemophiliasocalcal.org	Inherited/Genetic Bleeding Disorders
Hereditary Neuropathy Foundation	https://www.hnf-cure.org/	Charcot Marie Tooth and Inherited Neuropathies
Hermansky-Pudlak Syndrome Network, HESA	www.hpsnetwork.org http://hesaonline.info	Hermansky-Pudlak Syndrome Autoimmune Encephalitis
Hope Life International	hlilife.org	All Rare Diseases with Focus in Sickle Cell Disease
Hope Life Support & Empowerment Initiative	www.hlsein.org.ng/	All Rare Diseases with Focus in Sickle Cell Disease
Hope4Harper	http://www.hope4harper.com	CDKL5
Hunter McAlpine	n/a	Hunter McAlpine
Hunters CMT4B3 Research Foundation Inc	http://cmt4b3research.org	Charcot-Marie-Tooth Disease Type 4B3
Huntington's Disease Youth Organization (HDYO)	en.hdyo.org	Huntington's Disease and Juvenile HD
Hyper IgM Foundation	www.hyperigm.org	Hyper IgM Syndrome
Hypersomnia Foundation	http://Hypersomniafoundation.org	Idiopathic Hypersomnia, Narcolepsy and Kleine-Levin Syndrome (KLS)
Hypertrophic Cardiomyopathy Association	4hcm.org	Hypertrophic Cardiomyopathy Spectrum Diseases
Hypertrophic Olivary Degeneration Association	http://www.HODAssoc.org	Hypertrophic Olivary Degeneration
HypoPARathyroidism Association, Inc	www.hypopara.org	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
IDefine	http://idefine.org	Kleefstra Syndrome
Illinois Spina Bifida Association	www.i-sba.org	Spina Bifida
INADcure Foundation	www.INADcure.org	Infantile Neuroaxonal Dystrophy
Inclusive Skating	http://www.inclusiveskating.org	All Diseases
Indian Prader Willi Syndrome Association India	http://www.ipwsa.com/	Prader Willi Syndrome, Chromosome 15(Q11-Q13)
Indo US Organization for Rare Diseases (IndoUSrare)	https://www.indousrare.org/	Disease Agnostic (All Rare Diseases)
Inspire Medical Communications, LCC	https://www.inspiremedicalcommunications.com/	Disease Agnostic (All Rare Diseases)
Intermountain PKU and Allied Disorders. Association	http://www.ipadutah.org	PKU and Other Inborn Errors of Metabolism
International FOP Association	http://www.ifopa.org	Fibrodysplasia Ossificans Progressiva (FOP)
International Foundation for CDKL5 Research	www.cdkl5.com	Cdkl5 Disorders
International Gaucher Alliance	www.gaucheralliance.org	Gaucher Disease
International Pain Foundation	www.internationalpain.org	Diseases Causing Chronic Pain
International Pemphigus Pemphigoid Foundation	https://www.pemphigus.org/	Pemphigus And Pemphigoid (Includes All Sub-Variants)

International Prader-Willi Syndrome Organisation	www.ipwso.org	Prader-Willi Syndrome
International WAGR Syndrome Association	http://www.wagr.org	WAGR Syndrome, Aniridia, Wilms tumor
Jamal's Helping Hands	www.jamalshelpinghands.org	Rare Disease
Jett Foundation	https://www.jettfoundation.org/	Duchenne Muscular Dystrophy
Jordan's Guardian Angels	https://jordansguardianangels.org/	Jordan's Syndrome (PPP2R5D, PPP2R1A, PPP2R5C)
Juju and Friends CLN2 Warrior Foundation	https://give.rarevillage.org/campaign/juju-and-friends-cln2-warrior-foundation/c386658	CLN2 Batten Disease
Kabuki Syndrome Foundation	kabuksyndromefoundation.org	Kabuki Syndrome
KBG Foundation	www.kbgfoundation.com	Kbg Syndrome
KBG Syndrome Association	n/a	Kbg Syndrome- Ankrd11
KCNT1 Epilepsy Foundation	https://kcnt1epilepsy.org/	Kcnt1 Related Epilepsy and Neurodevelopmental Disorders
KDM5C KARES Foundation	kdm5cfoundation.org	KDM5C Related Genetic Disorders
KIF1A.ORG	www.KIF1A.org	KIF1A Associated Neurological Disorder (KAND)
Koolen-de Vries Syndrome Foundation	www.kdvsfoundation.org	Koolen-De Vries Syndrome Foundation
Let Go Skate Co.	http://Letgoskateco.com	Nail Patellar Syndrome
LGMD Awareness Foundation, Inc.	https://www.lgmd-info.org/	30+ Subtypes Of Limb-Girdle Muscular Dystrophy (Lgmd)
Life and Family Foundation, VA	www.sicklecellva.org	Sickle Cell Disease
Life Branches NFP Inc	www.lifebranches.org	All Rare Diseases
Lightning and Love Foundation	www.lightningandlove.org	Thap12 Recessive Genetic Disease
Littlest Tumor Foundation	https://littlesttumor.org	Neurofibromatosis
Living with Holt-Oram Syndrome	https://www.facebook.com/groups/livingwithholtoramssyndrome/?ref=share	Holt-Oram Syndrome
Louisiana Metabolic Disorders Coalition	http://louisianamdc.org	Metabolic Disorders-Amino Acid/Fatty Oxidation Disorders
Lymphangiomatosis & Gorham's Disease Alliance	https://www.lgdalliance.org/	Complex Lymphatic Anomalies Including Generalized Lymphatic Anomaly, Gorham Stout Disease, Kaposiform Lymphangiomatosis And Central Conducting Lymphatic Anomaly
Lysosomal Storage Disorders Society - Pakistan	www.lsdpk.org	All Lysosomal Storage Disorders
Lysosomal Storage Disorders Support Society	https://lsdssindia.org/	Lysosomal Storage Disorders
Malan Syndrome Foundation	malansyndrome.org	Malan Syndrome
MarylandRARE	https://marylandrare.org/	Disease Agnostic (All Rare Diseases)
MCT8-AHDS Foundation	www.mct8.info	MCT8 Deficiency also called Allan-Herndon-Dudley Syndrome
MECP2 Duplication Foundation	http://www.mecp2d.org	MECP2 Duplication Syndrome
Meg's Miracles	www.megsmiracles.org	Stiff Person Syndrome (Pediatric And Adult Onset)
Melanin Children Matter Inc	melaninchildrenmatter.org	Sptlc2 Gene Mutation/ Pediatric Als
MEPAN Foundation	https://www.mepan.org	MEPAN Syndrome

Mesothelioma Applied Research Foundation	www.curemeso.org	Mesothelioma
Miracle For Madison & Friends	http://www.miracleformadison.org/	Spinal Muscular Atrophy
Mission: Cure	mission-cure.org	Chronic And Recurrent Acute Pancreatitis
Mississippi Metabolics Foundation	https://www.msmetabolics.org/	Genetic Metabolic Disorders/Inborn Errors Of Metabolism (Iem).
MLD Foundation	https://MLDfoundation.org	Metachromatic Leukodystrophy
Moebius Syndrome Foundation	http://www.moebius syndrome.org	Moebius Syndrome
Moonshots for Unicorns	https://moonshotsforunicorn.s.org/	PGAP3-CDG, CDG, GPI Anchor Disorders, Single Gene Neurologic Disorders
Morquio Community	www.Morquiocommunity.org	Morquio Syndrome (MPS IV)
MSL3 Syndrome Foundation	http://msl3.org	MSL3 Syndrome, Basilicata-Akhtar Syndrome
MTM-CNM Family Connection	www.mtm-cnm.org	Myotubular Myopathy and Centronuclear Myopathy
My Faulty Gene	https://myfaultygene.org	Hereditary Cancers, Hereditary Heart Diseases
My Little Sunshine Foundation	www.mylittlesunshine.org	Infertility And Cancer
Myhre Syndrome Foundation	https://www.myhresyndrome.org/	Myhre Syndrome
Myositis Support and Understanding	https://understandingmyositis.org	Idiopathic Inflammatory Myopathies - Polymyositis, Dermatomyositis, Inclusion Body Myositis, Immune Mediated Necrotizing Myopathy, Antisynthetase Syndrome
National Ataxia Foundation	ataxia.org	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	https://www.nfed.org/	Ectodermal Dysplasias
National Fragile X Foundation	https://fragilex.org/	Fragile X Syndrome; Fragile X-associated Tremor/Ataxia Syndrome; Fragile X-associate Primary Ovarian
National Gaucher Foundation of Canada	www.gauchercanada.ca	Gaucher Disease
National Organization for Disorders of the Corpus Callosum	nod.org	Agenesis of the Corpus Callosum, Hypoplasia of the Corpus Callosum, Disorders of the Corpus Callosum
National Organization of African Americans with Cystic Fibrosis	https://noaacf.org/	Cystic Fibrosis
National PKU Alliance	https://www.npkua.org	National PKU Alliance
National PKU News	https://pkunews.org	PKU and Similar Inborn Errors of Metabolism
NBIA Disorders Association	www.NBIAdisorders.org	Neurodegeneration With Brain Iron Accumulation (Nbia) - 10 Different Disorders Under Our Umbrella.
NCBRS Worldwide Foundation	http://www.ncbrs.com	Nicolaides-Baraitser Syndrome
Neuroendocrine Cancer Awareness Network Inc	netcancerawareness.org	Neuroendocrine, Carcinoid, Carcinoid Syndrome
Neuromuscular Disease Foundation	www.CureGNEM.org	Gne Myopathy
Nevus Outreach	http://www.nevus.org	Congenital Melanocytic Nevi and Related Disorders Including Neurocutaneous Melanosis and Melanoma

New York City Hemophilia Chapter	www.nyhemophilia.org	Hemophilia
New Zealand Amyloidosis Patients Association	www.amyloidosis.co.nz	Amyloidosis
New Zealand Pompe Network	https://www.nzpompe.network/	Pompe Disease
NF2 BioSolutions	https://nf2biosolutions.org/	Neurofibromatosis Type 2
NGO «Rare Diseases of Ukraine»	https://www.facebook.com/orphandisua	Orphan Diseases
NGO Association of Patients with Pulmonary Hypertension	pha.org.ua	Pulmonary Hypertension
Our Odyssey	https://ourodyssey.org/	Disease Agnostic (All Rare Diseases)
Pan African Vision for the Environment(PAVE)	n/a	All Rare Diseases in Nigeria
Parent it Forward Corporation	https://parentitforward.org/	Children with a Rare or Not Rare Diseases
Parent Project Muscular Dystrophy	www.ppmindia.org	Duchenne Muscular Dystrophy
Pathways for Rare and Orphan Studies	www.prosfoundation.org	Rare and Undiagnosed Diseases
Pathways To Trust	www.pathwaystotrust.org	Sickle Cell Disease; Ehlers-Danlos Syndrome
Patient Advocate Foundation	www.patientadvocate.org	Any Chronic, Life-Threatening Or Debilitating Disease
PBC Foundation	www.pbcfoundation.org.uk	Primary Biliary Cholangitis
Peer Medical Foundation	https://peermedfoundation.org/	All Disease or Genetic Conditions
People With Empathy	www.peoplewithempathy.org	Rare disease/Autoimmune (general)
Petronille Healthy Society	https://www.petronillehealthy.society.org/	Blood Diseases and Disorders
Platelet Disorder Support Association	https://pdsa.org/	Immune Thrombocytopenia (ITP)
PO"UAP PKU "Special children"	http://www.detipku.org.ua/	Phenylketonuria
PPP3CA	www.ppp3ca.org	Mutation On Ppp3Ca Gene
Prader-Willi Syndrome Association USA	http://www.pwsausa.org	Prader-Willi Syndrome
PRISMS, Inc.	www.prisms.org	Smith-Magenis Syndrome
Progressive Familial Intrahepatic Cholestasis Advocacy and Resource Network	http://www.pfic.org	PFIC and PFIC Related Diseases
Project 8p Foundation	https://project8p.org	Chromosome 8p Disorder
Project Alive	https://projectalive.org/	Mucopolysaccharidosis (MPS II)
Project Clio	http://www.projectclio.org	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	https://www.projectfava.org	Fibro-Adipose Vascular Anomalies (Fava)
Project Sebastian	http://www.projectsebastian.org	Primarily Batten
PVNH Support & Awareness	www.PVNHsupport.com	X-Linked Periventricular Nodular Heterotopia, Grey Matter Heterotopia, Subcortical Heterotopia, Subcortical Band heterotopia
Pyruvate Kinase Deficiency Foundation	pkdf.org	Pyruvate Kinase Deficiency

Raising Hope International Friends	www.raisinghopeinternational.org	Sickle Cell Disease
Rare Disease Ghana Initiative	www.rarediseaseghana.org	All Rare Diseases
Rare Disease Male Mental Health Support Group	https://www.facebook.com/groups/991558431661517/	All Rare Diseases
Rare Diseases South Africa NPC	www.rarediseases.co.za	All Rare Conditions
Rare Disorders Kenya	www.rarediseasekenya.org	All Rare Diseases
Rare Families Canada	n/a	Rare And Chronic Diseases (Disease Agnostic)
Rare Village Foundation	https://rarevillage.org	All Rare Disease
RareKC	www.rarekc.org	All Rare Diseases in The Region
RASopathies Network	https://RASopathiesNet.org	RASopathies, Namely CFC, Costello and the Noonan Syndromes
Raymond A. Wood Foundation	https://www.rawoodfoundation.org/	Craniopharyngioma
Recurrent Respiratory Papillomatosis Foundation	www.rrpf.org	Recurrent Respiratory Papillomatosis, Laryngeal Papillomatosis, Pulmonary Rrp, Tracheal Papillomatosis, Lung Cancer
Remember The Girls	rememberthegirls.org	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	https://sappanifoundation.com/	Rare Diseases And Congenital Disorders Of Glycosylation (Cdg)
SATB2 Gene Foundation	www.satb2gene.org	Satb2-Associated Syndrome (Aka Glass Syndrome)
SCN2A Asia Pacific	www.scn2aaustralia.org	Scn2A - Autism Or Epilepsy
SCN2A GEORGIAN ASSOCIATION	n/a	Scn2A Gene
SETBP1 Society	https://setbp1.org	SETBP1 Haploinsufficiency Disorder, SETBP1-related Disorder
Shwachman-Diamond Syndrome Alliance Inc	www.SDSAlliance.org	Shwachman-Diamond Syndrome
Sickle Cell 101	https://www.sc101.org/	Sickle Cell Disease
SICKLE CELL AWARENESS FOUNDATION CORP INT	www.scafci.org	Sickle Cell Disease/Sickle Cell Trait
Sickle Cell Coalition of Maryland	n/a	Dreamsickle
Sickle Cell Foundation of MN	www.sicklecellmn.org	Sickle Cell Disease
Sickle Cell Reproductive Health Education Directive	http://www.sicklecellred.org	Sickle Cell and Sickle Cell Trait
Siegel Rare Neuroimmune Association	https://wearesrna.org/	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	http://www.sistershopefoundation.org	ALSP, CSF1R Related Leukoencephalopathy
SLC6A1 Connect	http://slc6a1connect.org	SLC6A1 Gene Mutation and Related Disorders
Soft Bones, Inc., The US Hypophosphatasia Foundation	www.softbones.org	Hypophosphatasia
Sophie's Hope Foundation, Inc	www.sophieshopefoundation.org	Glycogen Storage Disease Type 1B

Special Education Teaching and Learning Inc.	https://teachrare.org	Aromatic L-Amino Decarboxylase Deficiency
Stronger Than Sarcoidosis	https://www.strongerthansarcoidosis.org/	Sarcoidosis
STXBP1 e.V.	https://stxbp1-ev.de	STXBP1 Encephalopathy and Disorder
STXBP1 Foundation	https://www.stxbp1disorders.org/	STXBP1 genetic disorders
Super T's Mast Cell Foundation	http://supertmastcell.org	Mast Cell Disease/Mastocytosis
Supporters of Families with Sickle Cell Disease, Inc	http://www.sicklecelloklahom a.org	Sickle Cell Disease and its Inherited Disorders and Traits
Syndromes Without A Name (SWAN) Australia	https://swanaus.org.au/	Undiagnosed and Rare Genetic Conditions
SynGAP Research Fund	https://www.syngapresearchfund.org	SYNGAP1
T.E.A.M. 4 Travis (Together Ending Asplenia Mortality)	www.team4travis.org	Isolated Congenital Asplenia
TANGO2 Research Foundation	tango2research.org	TANGO2-Related Disorder
Tatton Brown Rahman Syndrome Community	https://tbrsyndrome.org	Tatton Brown Rahman Syndrome
Team Telomere	http://teamtelomere.org	Telomere Biology Disorders
Team Titin	https://titinmyopathy.com/	Titin Related Muscle and Heart Disorders
TED Community Foundation	https://tedcommunity.org	Thyroid Eye Disease (TED)
Teddington Trust	http://www.teddingtontrust.com	Xeroderma Pigmentosum
TESS Research Foundation	tessresearch.org	SLC13A5 Epilepsy, a Citrate Transporter Disorder
The Akari Foundation	theakarifoundation.org	Duchenne Muscular Dystrophy
The Allo Hope Foundation	www.allohopefoundation.org	Maternal Alloimmunization and HDFN (Hemolytic Disease of the Fetus and Newborn)
The Assistance Fund	http://www.assistfund.org	Multiple Sclerosis, Cystic Fibrosis, Advanced Breast Cancer, Parkinson's
The Bonnell Foundation: Living with Cystic Fibrosis	https://thebonnellfoundation.org	Cystic Fibrosis
The Champ Foundation	https://www.thechampfoundation.org/	Single Large-scale Mitochondrial Deletion Syndromes (SLSMDS), like Pearson Syndrome
The Chandler Project	https://thehandlerproject.org/	Achondroplasia, Dwarfism, Skeletal Dysplasias
The Children's Rare Disorders Fund	http://www.thecrdfund.org	Rare Genetic Disorders
The Cute Syndrome Foundation	https://www.thecutesyndrome.com/	SCN8A Disorders
The Dynamite Foundation Inc	http://ifightlikedynamite.org	Histiocytosis: LCH, HLH, ECD, RDD, JXG
The E.WE Foundation	www.theewefoundation.org	Edwards Syndrome, Trisomy 18
The Ehlers-Danlos Society	https://www.ehlers-danlos.com/	Eds And Hsd
The Global Foundation for Peroxisomal Disorders	www.thegfpd.org	Peroxisomal Disorders In The Zellweger Spectrum And The Related Single Enzyme Protein Deficiencies
The Jansen de Vries Syndrome Foundation	https://jansen-devries.org/	Jansen de Vries Syndrome
The Jansen's Foundation	https://www.thejansensfoundation.org/	Jansen's Metaphyseal Chondrodysplasia
The JDS Foundation	https://www.facebook.com/gr	Primary Mediastinal Germ Cell Tumors

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The KCNC1 Foundation	http://www.kcnc1.org	KCNC1-Related Disorders: Epilepsy, NDD, Autism, ID, DD
The Marfan Foundation	http://Marfan.org	Marfan Syndrome, Loey's-Dietz Syndrome, Vascular Ehlers-Danlos Syndrome
The Mast Cell Disease Society	www.tmsforacure.org	Mastocytosis and Variants, Mast Cell Activation Syndrome, Hereditary Alpha Tryptasemia
The Menkes Foundation	http://www.themenkesfoundation.org	Menkes Disease
The MOG Project	https://mogproject.org/	Myelin Oligodendrocyte Glycoprotein Antibody Disease (MOGAD)
The PURA Syndrome Foundation	purasyndrome.org	Genetic Conditions
The Scheuermann's Disease Fund	www.sdfund.org	Scheuermann's Disease
The SHANK2 Foundation	shank2.org	Shank2 Disorder
The Stiff Person Syndrome Research Foundation	https://stiffperson.org	Stiff Person Syndrome
The TBCK Foundation	www.tbckfoundation.com	Tbck Syndrome
The XLH Network, Inc.	xlhnetwork.org	X-Linked Hypophosphatemia
ThinkGenetic Foundation	http://thinkgenetic.org	All Rare Diseases
Thrive with Pyruvate Kinase Deficiency Organization	https://thrivewithpkd.org/	Pyruvate Kinase Deficiency
Timothy Syndrome Alliance	www.timothysyndrome.org	Cacna1C-Related Disorders, Timothy Syndrome, Longqt8
Tin Soldiers Global FOP Patient Search	www.tinsoldiers.org	Fibrodysplasia Ossificans Progressiva (FOP) and Broader Musculoskeletal Conditions
To Cure a Rose Foundation	tocurearose.org	HNRNP2 and Other Similar Monogenic Rare Diseases
Transplant Unwrapped	www.transplantunwrapped.org	Intestinal Failure, Short Bowel Syndrome, HPN Nutrition, Gastroparesis, CIPO
TSC Alliance	https://www.tscalliance.org/	Tuberous Sclerosis Complex
Turner Syndrome Global Alliance	http://tsgalliance.org/	Turner Syndrome (TS)
Undiagnosed Diseases Network Foundation (UDNF)	http://UDNF.org	Undiagnosed / Misdiagnosed/New Ultra Rare Diseases
Unfixed	http://www.unfixedmedia.com	All Rare Diseases
United For Scleroderma	n/a	Scleroderma
United Mitochondrial Disease Foundation	www.umdf.org	Mitochondrial Disorders
United MSD Foundation	https://curemsd.org/	Multiple Sulfatase Deficiency
United Porphyrias Association	http://www.porphyria.org	Porphyria
Upequity	http://www.upequity.org	All Rare and Chronic Health Conditions
Uplifting Athletes Inc.	www.upliftingathletes.org	Disease Agnostic (All Rare Diseases)
Uriel E. Owens Sickle Cell Disease Association of the Midwest	www.sicklecellmidwest.org	Sickle Cell Disease and Sickle Cell Trait
Usher 1F Collaborative	https://www.usher1f.org	Usher Syndrome Type 1F
Usher Syndrome Coalition	www.usher-syndrome.org	Usher Syndrome
VICKtorious (formerly Rareability)	www.vicktorious.org	Autoimmune Conditions - Primary Immunocompromised
Vidas Raras Institute	http://www.vidasraras.org.br	Rare Diseases
Virginia Sickle Cell Network	http://www.vasicklecellnetwork.org	Sickle Cell

Vision for Tomorrow Foundation	https://visionfortomorrow.org	Aniridia, Albinism
wAIHA Warriors	waihawarriors.org	Warm Autoimmune Hemolytic Anemia
We are Familial ALS	https://www.facebook.com/familialals/	Pre-Manifest Genetic ALS
Wilhelm Foundation	www.wilhelmfoundation.org	Undiagnosed Diseases
William E. Proudford Sickle Cell Fund Inc.	wepsicklecell.org	Sickle Cell Disease And Trait
WonderFIL Smiles	https://wonderfilsmiles.com/	The PROS (PIK3CA Related Overgrowth Spectrum) Condition FIL (Facial Infiltrating Lipomatosis)
Wylder Nation Foundation	WylderNation.org	Niemann-Pick Disease/Acid Sphingomyelinase Deficiency (ASMD)
YBRP, Inc	http://ybrp.org	HNRNP2 Related Disorder
Youngtimers, Inc.	youngtimers.org	Early Onset Familial Alzheimer's Disease
Youth and Women for Opportunities Uganda-YWOU	https://www.facebook.com/YWOUg/	All Rare Diseases, Neuromuscular, Lysosomal Storage Disorders, Inherited Metabolic Disorders
Zebra CARE Initiative	https://zebra-care.org/	Ehlers Danlos Syndrome
Zoe's Story	https://zoestory.org/ https://zoestory.org/	CRMO and All Children Facing Serious Rare Illnesses
ZTTK SON-Shine Foundation	http://www.zttksonshinefoundation.org	ZTTK Syndrome

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