



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
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-Forsman-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 Memebrs
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.mppsociety.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 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
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 Mito Foundation	https://www.curemito.org	Leigh syndrome, Mitochondrial Diseases
Cure Mucopolysaccharidosis	www.curemucopolysaccharidosis.org	Mucopolysaccharidosis II Mucopolysaccharidosis III Mucopolysaccharidosis III and Sialidosis
Cure Rare Disease	https://www.curerare.disease.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
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	ericjourney.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 reffered as Glass Syndrome (Nevrodevelopmental dDorder, 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
FAM177A1 RESEARCH FUND	http://www.fam177a1.org	FAM177A1 Associated Disease
FamilieSCN2A Foundation	www.scn2a.org	Scn2A
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)
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)
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.helpholive.org	Transplant, Spinal Cord Injury, EDS, FOXG1, 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,	www.hpsnetwork.org	Hermansky-Pudlak Syndrome
HESA	http://hesaonline.info	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
Hunter McAlpine	n/a	Hunter McAlpine
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 Pidd, Ehlers-Danlos Syndrome, Pots, Gastroparesis, & All Other Rare Diseases
I am in PAIN and yet I LAUGH	n/a	Pediatric Patients
iCAN KIDS DRC	n/a	Kleefstra Syndrome
IDefine	http://idefine.org	Spina Bifida
Illinois Spina Bifida Association	www.i-sba.org	Infantile Neuroaxonal Dystrophy
INADcure Foundation	www.INADcure.org	All Diseases
Inclusive Skating	http://www.inclusiveskating.org	Prader Willi Syndrome, Chromosome 15(Q11-Q13)
Indian Prader Willi Syndrome Association India	http://www.ipwsa.com/	Disease Agnostic (All Rare Diseases)
Indo US Organization for Rare Diseases (IndoUSrare)	https://www.indousrare.org/	Disease Agnostic (All Rare Diseases)
Inspire Medical Communications, LCC	https://www.inspiremedicalcommunications.com/	PKU and Other Inborn Errors of Metabolism
Intermountain PKU and Allied Disorders. Association	http://www.ipadutah.org	Fibrodysplasia Ossificans Progressiva (FOP)
International FOP Association	http://www.ifopa.org	Cdk15 Disorders
International Foundation for CDKL5 Research	www.cdk15.com	Gaucher Disease
International Gaucher Alliance	www.gaucheralliance.org	Diseases Causing Chronic Pain
International Pain Foundation	www.internationalpain.org	Pemphigus And Pemphigoid (Includes All Sub-Variants)
International Pemphigus Pemphigoid Foundation	https://www.pemphigus.org/	Prader-Willi Syndrome
International Prader-Willi Syndrome Organisation	www.ipwso.org	WAGR Syndrome, Aniridia, Wilms tumor
International WAGR Syndrome Association	http://www.wagr.org	Rare Disease
Jamal's Helping Hands	www.jamalshelpinghands.org	Duchenne Muscular Dystrophy
Jett Foundation	https://www.jettfoundation.org/	Jordan's Syndrome (PPP2R5D, PPP2R1A, PPP2R5C)
Jordan's Guardian Angels	https://jordansguardianangels.org/	CLN2 Batten Disease
Juju and Friends CLN2 Warrior Foundation	https://give.rarevillage.org/campaign/juju-and-friends-cln2-warrior-foundation/c386658	Kabuki Syndrome
Kabuki Syndrome Foundation	kabuksyndromefoundation.org	Kbg Syndrome
KBG Foundation	www.kbgfoundation.com	Kbg Syndrome- Ankrd11
KBG Syndrome Association	n/a	Kcnt1 Related Epilepsy and Neurodevelopmental Disorders
KCNT1 Epilepsy Foundation	https://kcnt1epilepsy.org/	KDM5C Related Genetic Disorders
KDM5C KARES Foundation	kdm5cfoundation.org	KIF1A Associated Neurological Disorder (KAND)
KIF1A.ORG	www.KIF1A.org	Koolen-De Vries Syndrome Foundation
Koolen-de Vries Syndrome Foundation	www.kdvsfoundation.org	Nail Patellar Syndrome
Let Go Skate Co.	http://Letgoskateco.com	

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/livingwithholtoram syndrome/?ref=share	Holt-Oram Syndrome
Louisiana Metabolic Disorders Coalition	http://louisianamdc.org	Metabolic Disorders-Amino Acid/Fatty Oxidation Disorders
lymphangiomas & gorham's disease alliance	https://www.lgdalliance.org/	Complex Lymphatic Anomalies Including Generalized Lymphatic Anomaly, Gorham Stout Disease, Kaposiform Lymphangiomas 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://moonshotsforunicorns.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 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://ourodysey.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)
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 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.sicklecelloklahoma.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
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 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 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/groups/506130270955118/	Primary Mediastinal Germ Cell Tumors
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 Trypsinemia
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
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
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.porphyrria.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
Wylder Nation Foundation	WylderNation.org	Niemann-Pick Disease/Acid Sphingomyelinase Deficiency (ASMD)
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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