



Global Genes RARE Foundation Alliance is made up of over 500 disease foundations 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.

[#Bold Lips For Sickle Cell](#) – Sickle Cell Disease

[11q Research & Resource Group](#) – Jacobsen Syndrome, 11q Chromosome

[1p36 Deletion Support & Awareness](#) – 1p36 Deletion Syndrome

[22q 11 Ireland support group](#) – 22q11.2 deletion syndrome

[4p- Support Group](#) – Wolf-Hirschhorn Syndrome and related 4p conditions

[5p-Society](#)– 5p- Syndrome, Cat Cry Syndrome, Cri du Chat Syndrome

[17q12 Foundation](#) - 17q12 Deletions and Duplications

[A Foundation Building Strength for Nemaline Myopathy](#) – Nemaline Myopathy

[A Nonprofit Group Enriching Lives \(ANGEL AID\)](#) - Multiple rare diseases

[Aaron's Ohtahara](#) – Ohtahara Syndrome

[Acid Maltase Deficiency Association](#)– Acid Maltase Deficiency, Pompe's Disease

[Acromegaly Community](#) – Acromegaly and Gigantism

[Acromegaly Ottawa Awareness & Support Network](#) - Acromegaly

[Acoustic Neuroma Association](#) – Acoustic Neuroma

[ADCY5.org](#) – ADCY5 Mutation

[Addi & Cassi Fund](#) – Niemann Pick Type C

[ADNPkids](#) – ADNP Syndrome, Helsmoortal\_Van Der AA Syndrome

[Adrenal Insufficiency United](#) – Adrenal Insufficiency

[Adult Polyglucosan Body Disease Research Foundation](#) (APBDRF) – APBD

[Advancing Sickle Cell Advocacy Project, Inc.](#) – Sickle Cell Disease

[Advocacy & Awareness for Immune Disorders Association](#) – Primary Immunodeficiency Diseases (PID), Hereditary Angioedema, Pediatric Acute onset Neuropsychiatric Syndrome (PANS), Autoimmune diseases

[AHC Federation of Europe](#) – Alternating Hemiplegia of Childhood

[Aicardi-Goutieres Syndrome Association of the Americas](#) (AGSAA)- Aicardi-Goutieres Syndrome

[Aidan Jack Seeger Foundation](#) – Adrenoleukodystrophy

[AKU Society](#) – Alkaptonuria

[AKU Society North America](#) – Alkaptonuria

[Alagille Syndrome Alliance](#) – Alagille Syndrome

[Alect2 Alliance](#) – Amyloidosis Alect2

[ALD Connect](#) – Adrenoleukodystrophy

[All Things Kabuki](#) – Kabuki Syndrome

[Alliance for Cryoglobulinemia](#) – Cryoglobulinemia

[Alliance for Safety Awareness for Patients](#) – Hospital-Acquired Necrotizing Fasciitis

[Alpha-1 Foundation](#) – Alpha-1 Antitrypsin Deficiency

[Alport Syndrome Foundation](#) – Alport Syndrome

[Alström Angels](#) – Alström Syndrome

[Alström Syndrome International](#) – Alström Syndrome

[Alternating Hemiplegia of Childhood Foundation](#) – Alternating Hemiplegia of Childhood

[AMENSupport](#) – Multiple Endocrine Neoplasia

[American Behcet’s Disease Association](#) – Behcet’s Disease

[American Partnership for Eosinophilic Disorders](#) – Eosinophilic Disorders

[American Society of Cell and Gene Therapy](#)

[American Prophyria Foundation](#) – Prophyria Disease

[Amour Fund of Alpha Epsilon Omega Foundation](#) – Congenital Disorders of Glycosylation (CDG)

[Amyloidosis Foundation, Inc.](#) – Amyloidosis

[Amyloidosis Research Consortium](#) – Amyloidosis

[Angelman Biomarkers and Outcome Measures Alliance](#) (A-BOM)

[Angelman Syndrome Foundation](#) - Angelman Syndrome

[Angels with Missing Pieces](#) – 22Q Deletion Syndrome

[Angioma Alliance](#) – Cavernous Angioma

[Appendix Cancer / Pseudomyxoma Peritonei Research Foundation](#) (ACPMP)- Pseudomyxoma Peritonei

[\*\*Aplastic Anemia and MDS International Foundation\*\*](#) – Aplastic anemia, Myelodysplastic syndromes, Paroxysmal nocturnal hemoglobinuria

[\*\*Arachnoiditis Society for Awareness and Prevention\*\*](#) – Arachnoiditis

[\*\*Arachnoiditis and Chronic Meningitis Collaborative Research Network\*\*](#)

[\*\*ARPKD/CHF Alliance\*\*](#) - Autosomal Recessive Polycystic Kidney Disease and Congenital Hepatic Fibrosis

[\*\*Asociación Española De Amiloidosis\*\*](#) - Amyloidosis

[\*\*Association for Creatine Deficiencies\*\*](#) – Creatine Transport Deficiency, Guanidinoacetate Methyltransferase Deficiency, L-Arginine: Glycine Amidinotransferase

[\*\*Association for Glycogen Storage Disease\*\*](#) – Glycogen Storage Disease

[\*\*Association of Peyronie’s Disease Advocates\*\*](#) – Peyronie’s disease

[\*\*AT Children’s Project\*\*](#) – Ataxia-Telangiectasia

[\*\*Atacsia a Fi – Ataxia and Me\*\*](#) – Ataxia

[\*\*Atlanta S.C.A.R., Inc\*\*](#) – Sickle Cell Disease

[\*\*A Twist of Fate\*\*](#) – Arterial tortuosity syndrome

[\*\*Atypical HUS Foundation\*\*](#) – Atypical Hemolytic Uremic Syndrome

[\*\*Autoimmune Hepatitis Association\*\*](#) – Autoimmune Hepatitis

[\*\*Autoinflammatory Alliance\*\*](#) – Cryopyrin-Associated Periodic Syndromes, Neonatal-Onset Multisystem Inflammatory Disease, Chronic Infantile Neurological Cutaneous and Articular Syndrome, Familial Cold Autoinflammatory Syndrome

[\*\*Aux Pas Du Coeur\*\*](#) – GNE Myopathy, Duchenne Muscular Dystrophy

[\*\*Avery’s Angels Gastroschisis Foundation\*\*](#) – Gastroschisis Disease

[\*\*Avery’s Hope\*\*](#)– GI Diseases

[\*\*Aware of Angels\*\*](#) – Multiple Rare Diseases

[\*\*AXYS\*\*](#) – One or more extra X and/or Y chromosomes

[\*\*Bardet Biedl Australia\*\*](#) – Bardet-Biedl Syndrome

[\*\*Barth Syndrome Foundation\*\*](#) – Barth Syndrome

[\*\*Batten Disease Support and Research Association\*\*](#) - Batten Disease

[\*\*Bcureful\*\*](#) – Tuberous Sclerosis Complex

[\*\*Beautiful You MRKH Foundation\*\*](#) – Mayer-Rokitansky-Küster-Hauser Syndrome

[\*\*Beckwith-Wiedemann Children's Foundation International\*\*](#) - Beckwith-Wiedemann Syndrome

[Ben's Dream](#) – Sanfilippo Syndrome

[Ben's Friends](#) – All Rare Diseases

[Bethany's Hope Foundation](#)

[Beyond Batten Disease Foundation](#) – Batten Disease

[BlackSwan Foundation](#) – Multiple Rare Diseases, Switzerland

[Blind Children's Learning Center](#) - Multiple Rare Diseases

[Bohring-Opitz Syndrome Foundation, Inc.](#) – Bohring-Opitz Syndrome

[Boomer Esiason Foundation](#) – Cystic Fibrosis

[Born a Hero](#) – Pfeiffer Syndrome

[BPAN Warriors](#)– Beta-Propeller Protein-Associated Neurodegeneration

[Breathe Support Network](#) - Pulmonary Fibrosis

[Bridge the Gap](#) – SYNGAP1

[CADASIL Together We Have Hope](#) – Cerebral Autosomal Dominant Arteriopathy  
Subcortical Infarcts Leukoencephalopathy

[California Action Link for Rare Diseases Inc. \(CAL RARE\)](#) – All Rare Diseases

[Care Beyond Diagnosis](#) – Multiple Rare Diseases

[Cailee's Corner](#) – Familia Exudative Vitreopathy (FEVR)

[Campbell Burns Metabolic Trust](#) – Metabolic Disorders

[Canadian Association of Pompe](#) – Pompe Disease

[Canadian Fabry Association](#) – Fabry Disease

[Canadian MPS Society](#)-Mucopolysaccharide and Related Diseases

[Canadian Organization for Rare Disorders](#) – Multiple Rare Diseases

[Canadian PKU & Allied Disorders](#) – Phenylketonuria

[Canadian Pituitary Patient Network](#) - Pituitary and Adrenal disorders

[CARES Foundation](#) – Congenital Adrenal Hyperplasia

[Caring Voice Coalition](#) – Multiple Rare Diseases

[Carion Fenn Foundation](#) – Syringomyelia, Arnold Chiari Malformatio

[Castleman Disease Collaborative Network](#) – Castleman Disease

[CCHS Family Network /CCHS Foundation](#) – Congenital Central Hypoventilation  
Syndrome

[CDG Care](#) – Congenital disorders of glycosylation

[CDH International](#) - Congenital Diaphragmatic Hernia

[CDKL5 Canada](#)

[CDKL5 Research Collaborative](#)

[Center for Chronic Illness](#)

[Central California Hemophilia Foundation](#) – Inherited Bleeding Disorders

[CFC International](#) – Cardio-Facio-Cutaneous Syndrome

[CHAMP1ResearchFoundation](#) – CHAMP1

[Champions Action Network](#)

[Chasing Life Project](#) – Multiple Rare Diseases

[Cheyanna's Champions 4 Children \(CC4C\)](#) – Multiple Rare Diseases & Undiagnosed

[chILD Foundation](#) – Interstitial Lung Disease

[Child Neurology Foundation](#) – Childhood Neurologic Disorders

[Children's Alopecia Project](#) – Alopecia

[Children's Cardiomyopathy Foundation](#) – Pediatric Cardiomyopathy

[Children's Cerebral Palsy Movement](#) – Multiple Rare Diseases

[Children's Craniofacial Association](#) – Craniofacial Disorders

[Children's Gaucher Research Foundation](#) – Gaucher Disease Types 2/3

[Children's Tumor Foundation](#) – Neurofibromatosis Disease

[Chinese Organization for Rare Disorders](#) – Multiple Rare Diseases

[Chion Foundation](#) – Prader-Willi Syndrome

[Chive Charities](#) – Multiple Rare Diseases

[Cholangiocarcinoma Foundation](#)

[Chordoma Foundation](#) – Chordoma, Sarcoma

[Choroideremia Research Foundation](#) – Choroideremia

[Chronic Intractable Pain And You Sites, Inc.](#) – Chronic and/or Intractable Pain

[Chronic Pain Partners](#)

[Cincinnati Comprehensive Sickle Cell Center at Cincinnati Children's Hospital](#) –

Sickle Cell Disease

[Citizens United for Research in Epilepsy](#) – Epilepsy

[CLOVES Syndrome Community](#) – CLOVES Syndrome

[CMTC-OVM US](#) – CMTC (Van Lohuizen Syndrome)

[Coalition Duchenne](#) – Duchenne Muscular Dystrophy

[Cold Agglutinin Disease Foundation](#) - Cold Agglutinin Autoimmune Hemolytic Anemia-Acquired

[Complex Child E-Magazine](#) – Multiple Pediatric Rare Diseases

[Congenital Hyperinsulinism International](#) – Congenital Hyperinsulinism

[Connecting Families Urea Cycle Disorders Foundation](#) - Urea Cycle Disorder

[Cook for Love, Inc.](#) - PKU and other IEM that require a low protein diet

[Coriell Institute for Medical Research](#) – Multiple Rare Diseases

[Cornelia de Lange Syndrome Foundation](#) – Cornelia de Lange Syndrome

[Costello Syndrome Family Network](#) – Costello Syndrome

[Courageous Faces Foundation](#) - Multiple Rare Diseases

[CPRS Forum](#) – Complex Regional Pain Syndrome

[CRMO Foundation](#) - Chronic Recurrent Multifocal Osteomyelitis

[CSNK2A1 Foundation](#)– Okur-Chung Neurodevelopmental Syndrome (OCNDS)

[CTNNB1 Syndrome Awareness Worldwide](#) - CTNNB1 Syndrome

[Cure AHC](#) - Alternating Hemiplegia of Childhood

[Cure CADASIL](#) -CADASIL

[Cure CMD](#) – Congenital Muscular Dystrophy

[Cure CMT4j/ Talia Duff Foundation](#)– Charcot Marie Tooth Disease, Type 4j (CMT4j)

[Cure Duchenne](#) – Duchenne Muscular Dystrophy

[Cure GM1 Foundation](#) – GM1 Gangliosidosis

[Cure HHT](#) – Hereditary Hemorrhagic Telangiectasia

[Cure JM Foundation](#) – Juvenile Myositis, Juvenile Dermatomyositis, Amyopathic Dermatomyositis and Juvenile Polymyositis

[CureLGMD2j Foundation](#)– Limb Girdle Muscular Dystrophy Type 2

[Cure RTD Foundation](#)– Riboflavin Transporter Deficiency Neuropathy

[Cure Sanfilippo Foundation](#) – Sanfilippo Syndrome

[Cure SMA](#) - Spinal Muscular Atrophy

[Cure Surf1](#) – SURF1 Leigh Syndrome

[Cure TBM](#)– TracheoBronchoMalacia

[Cures Within Reach](#) – Multiple Rare Diseases

[Cure VCP Disease](#)

[CureGRIN](#) - GRIN

[Curing Retinal Blindness Foundation](#) – Leber’s Congenital Amaurosis, Retinitis Pigmentosa

[Cushing’s Support and Research Foundation](#) – Cushing’s Syndrome

[Cutaneous Lymphoma Foundation](#) – Cutaneous Lymphoma Disease

[Cyclic Vomiting Syndrome Association](#) – Cyclic Vomiting Syndrome

[Cystic Fibrosis Research, Inc.](#) – Cystic Fibrosis

[Cystinosis Research Network](#) – Cystinosis

[Dana’s Angels Research Trust](#) – Niemann Pick Type C

[Danny’s Dose Alliance](#) – Rare Diseases, Chronic Illness

[Daphne’s Lamp](#)

[debra of America](#) - Epidermolysis Bullosa

[Defeat MSA](#) - Multiple System Atrophy

[Determinence, Inc.](#) - Multiple Rare Diseases

[DHPS Foundation](#)

[DNA Checkup](#) – Recessive Genetic Disorders

[Dravet Syndrome Foundation](#) – Dravet Syndrome

[Dreamsickle Kids Foundation](#) - Sickle Cell Disease

[Drépanovie- Association des Drépanocytaires de Côte D'Ivoire](#) - Sickle Cell Anemia

[Dup15q Alliance](#) – Chromosome 15q Duplication Syndrome

[DYRK1A Community](#) – DYRK1A

[Dystonia Medical Research Foundation](#) – Dystonia

[EB Research Partnership](#) – Dystrophic Epidermolysis Bullosa

[EDMD International, Inc.](#) – Emery-Dreifuss Muscular Dystrophy

[EDSers United](#) – Ehlers Danlos Syndrome

[Ehlers-Danlos Network CARES Foundation](#) – Ehlers Danlos Syndrome

[Ehlers-Danlos Support Group of Greater Kansas City](#) – Ehlers Danlos Syndrome

[Ehlers-Danlos Support Group of Jacksonville](#) - Ehlers Danlos Syndrome

[Emerie Lee Foundation](#) - Childhood Blindness

[Encephalitis Society](#) - Encephalitis

[Endosalpingiosis Foundation Inc](#)– Endosalpingiosis

[Emily’s Entourage](#) – Cystic Fibrosis

[Epidermoid Brain Tumor Society](#) – Epidermoid brain tumor

[Epilepsy Warriors Foundation](#) – Epilepsy

[Erdheim-Chester Disease Global Alliance](#) – Erdheim-Chester Diseases

[Ethan Lindberg Foundation](#) – Congenital Heart Disease

[Ethan's Reason](#) – Batten Disease

[EveryLife Foundation](#) – Multiple Rare Diseases

[Fabry Australia](#) – Fabry Disease

[Fabry Support and Information Group](#) – Fabry Disease

[Familial Adenomatous Polyposis Foundation](#) – Familial Adenomatous Polyposis

[FamilieSCN2a Foundation](#) – SCN2a gene mutations

[FCS Foundation](#) – Familial Chylomicronemia Syndrome

[Feeding Tube Awareness Foundation](#) – Multiple Rare Diseases

[FH Foundation](#) – Familial Hypercholesterolemia

[Fibromuscular Dysplasia Society of America](#) – Fibromuscular Dysplasia

[Fibrous Dysplasia Foundation](#) – McCune Albright syndrome, Fibrous dysplasia

[Fighting H.A.R.D. Foundation](#) – Rare Disease, Chronic Illness

[Findacure](#) – Multiple Rare Diseases

[FIRST: Foundation for Ichthyosis & Related Skin Types](#) – Skin Diseases, Ichthyosis

[FMD Chat](#) – Fibromuscular dysplasia

[FMF & AID Global Association](#) – Familial Mediterranean Fever & Autoinflammatory Diseases

[Foundation for Angelman Syndrome Therapeutics](#) – Angelman Syndrome

[Foundation for Batten Hope](#) – Batten Hope

[Foundation for Mitochondrial Medicine](#) – Mitochondrial and Related Diseases

[Foundation for Prader-Willi Research](#) – Prader-Willi Syndrome, abnormal chromosome 15 (15q11-q13).

[Foundation for Sarcoidosis Research](#) – Sarcoidosis

[FPIES Foundation](#) – Food Protein-Induced Enterocolitis Syndrome

[Friedreich's Ataxia Research Alliance](#) – Friedreich's Ataxia

[Fundación Red Sanfilippo](#) – Sanfilippo Syndrome / MPS III

[GACI Global](#) - Generalized Arterial Calcification of Infancy

[Garrett the Grand](#) – Batten Disease

[Gaucher Association of Australia & New Zealand](#) - Gaucher



[GBS/CIDP Foundation International](#) – Guillain-Barré Syndrome, Chronic Inflammatory Demyelinating Polyneuropathy

[Gene Giraffe Project](#) – Multiple Rare Diseases

[Genetic Alliance UK](#) – Multiple Rare Diseases

[Genetic Aortic Disorders Association](#) - Canada - Aortic Disorders

[Glut1 Deficiency Foundation](#) - Glut1 Deficiency

[Global Hydranencephaly Foundation](#) – Hydranencephaly

[GNE Myopathy International](#) – GNE Myopathy, Hereditary Inclusion Body Myopathy , HIBM

[GRIN2B Foundation](#)

[Grupo De Estudos Doencas Raras](#) –Multiple Rare Diseases, Brazil

[Gwendolyn Strong Foundation](#) – Spinal Muscular Atrophy

[Hadley Hope Fund](#) – Niemann-Pick Type C disease

[HAE Canada](#) – Hereditary Angioedema

[Hairy Cell Leukemia Foundation](#) - Hairy Cell Leukemia

[Hannah's Hope Fund](#) – Giant Axonal Neuropathy

[Harmony 4 Hope](#) – Multiple Rare Diseases

[Harry's Fund](#) – Cri du Chat syndrome

[Haystack Project](#) - Multiple Rare Diseases

[HCU Network America](#) - Homocystinurias

[HD-Care](#) – Huntington's Disease

[Health Advocacy Summit](#)– Chronic Disease

[Help 4 HD International](#) – Huntington's disease

[Helping Hands for GAND, Inc.](#) – GATAD2B-associated neurodevelopmental disorder

[Hemophilia Foundation of Southern California](#)– Genetic Bleeding Disorders

[Hepatitis Foundation International](#) – Hepatitis

[Hereditary Angioedema Association](#) – Hereditary Angioedema

[Hereditary Hemorrhagic Telangiectasia Foundation International](#) – Hereditary Hemorrhagic Telangiectasia

Highway of Hope

[Histiocytosis Association](#) – Histiocytic Disorders, Langerhans Cell Histiocytosis

[Hope 4 Bridget Foundation](#) – Batten Disease

[Hope4tylerandluke](#) - Med 23 gene defect

[Hope for Hypothalamic Hamartomas](#) - Hypothalamic Hamartomas

[Hope for Javier](#) – Duchenne Muscular Dystrophy

[HOPE for SCD](#) – Sickle Cell Disease

[Hope for Trisomy 13 & 18](#) – Trisomy 13 & 18 and related disorders, Edwards and Patau Syndrome.

[HPS Network](#) – Hermansky-Pudlak Syndrome

[HSAN1E Society](#) – Hereditary Sensory and Autonomic Neuropathy, Type 1E

[HudsonAlpha Institute for Biotechnology](#)

[Huntington's Disease Society of America, Inc.](#) – Huntington's Disease

[Huntington's Disease Youth Organization \(HDYO\)](#)

[Hydrocephalus Association](#) – Hydrocephalus

[HyperIGM Foundation](#) – Hyper IGM Syndrome

[Hypoparathyroidism Association](#) – Hypoparathyroidism

[iCAN Research](#) - Multiple Rare Diseases

[Idic15 Canada](#)– Chromosome 15q11.2-13.1 Duplication Syndrome

[IFAA International Foundation for Autoimmune and Autoinflammatory Arthritis](#)

[IHope Foundation](#) – Intracranial Hypertension

[Illinois Spina Bifida Association](#) - Spina Bifida

[INADcure](#) - Infantile Neuroaxonal Dystrophy

[Incontinentia Pigmenti International Foundation](#) – Incontinentia Pigmenti

[Intermountain PKU and Allied Disorders Association](#) – Phenylketonuria and allied disorders

[International Cystinuria Foundation](#) – Cystinuria

[International Essential Tremor Foundation](#) – Essential Tremor

[International Firefighter Cancer Foundation, Inc.](#) – Multiple Rare Cancers

[International FOP Association](#) – Fibrodysplasia Ossificans Progressiva, Myositis Ossificans Progressiva

[International Foundation for CDKL5 Research](#)

[International FOXP1 Foundation](#) – FOXP1 gene mutation

[International Pemphigus & Pemphigoid Foundation](#) – Pemphigus, Pemphigoid

[International WAGR Syndrome Association](#) – WAGR Syndrome, 11p Deletion Syndrome

[IRF2BPL Foundation](#) - IRF2BPL Disorder

[ISMRD The International Advocate for Glycoprotein Storage Diseases](#) – Glycogen Storage Disease

[Jain Foundation](#) - Limb Girdle Muscular Dystrophy type 2B/R2/Mioyshi Myopathy/Dysferlinopathy

[Jamal's Helping Hands](#) - Multiple Chronic Illnesses

[Jamie's Dream Team](#) – Multiple Rare Diseases

[Jett Foundation](#) – Duchenne Muscular Dystrophy

[Jonah's Just Begun](#) – Sanfilippo Syndrome, Mucopolysaccharidoses (MPSIII)

[Joshua Frase Foundation](#) – Myotubular Myopathy

[Joshua Hellmann Foundation for Orphan Disease](#) – Multiple Rare Diseases, Hong Kong

[Joubert Syndrome & Related Disorders Foundation](#) – Joubert Syndrome

[Judson's Legacy](#) – Krabbe's Disease

[Kabuki Syndrome USA](#) –Kabuki syndrome

[KCNQ2 Cure](#) – KCNQ2

[KIF1A.org](#)

[Klippel-Feil Syndrome Freedom](#) – Klippel-Feil Syndrome

[Kneading Hope](#) – Multiple Rare Diseases

[KnowTheGlow](#) - Multiple Rare Diseases

[Koolen-de Vries Syndrome Foundation](#) - Koolen-de Vries Syndrome

[KrabbeConnect](#) – Krabbe

[Kruzn for a Kure Foundation](#) - Shimke Immuno Osseous Dysplasia

[K-T Support Group](#) – Klippel-Trenaunay Syndrome

[Kure for Kulas](#) – Spinal muscular atrophy (SMA)

[LAL Solace, Inc.](#) – Lysosomal Acid Lipase disease, LAL Deficiency, Wolman Disease

[Layla's Hope Foundation](#) – KCTD7 (Progressive Myoclonic Epilepsy Type 3)

[Lauren's Hope](#) – Hypomagnesemia with Secondary Hypocalcemia (HSH)

[Legg Calve Perthes Foundation](#) – Legg-Calve-Perthes Disease

[Leiomyosarcoma Direct Research Foundation](#) – Leiomyosarcoma

[LEMS Patients](#) – Lambert-Eaton Myasthenic Syndrome

[LGS Foundation](#) – Lennox-Gastaut Syndrome

[LHON Project](#) – Leber Hereditary Optic Neuropathy

[Li-Fraumeni Syndrome Association](#)– Li-Fraumeni Syndrome

[Lipodystrophy United](#) – Lipodystrophy

[Lipoprotein\(a\) Foundation](#) – High Lipoprotein(a)

[Little Hercules Foundation](#)– Duchenne Muscular Dystrophy

[Little Miss Hannah Foundation](#) – Multiple Pediatric Rare Diseases

[Littlest Tumor Foundation](#) - Neurofibromatosis

[Living in the Light of Rare Diseases](#) - Multiple Rare Diseases

[Live4TheCure](#) – All Rare Diseases

[Living LFS](#) – Li-Fraumeni Syndrome

[LouLou Foundation](#) – CDKL5 Deficiency Disorder

[Lowe Syndrome Association](#)– Lowe Syndrome

[LSD Society](#)– LSD, Pakistan

[Luka the Lion Foundation](#) – Multiple Pediatric Rare Diseases

[Lymphangiomatosis & Gorham’s Disease Alliance](#) – Lymphangiomatosis, Gorham’s Disease

[Lynch Syndrome International](#) – Lynch Syndrome

[Lysosomal Diseases New Zealand](#)

[Lysosomal Storage Disorders Support Society](#)– Lysosomal Diseases, India

[M-CM Network](#) – Macrocephaly-capillary malformation

[Mackenzie’s Mission](#) - Amyloidosis

[Malan Syndrome Foundation](#) - Malan Syndrome

[Marrow For Life, Inc.](#) – Stem Cell Treatments for Rare Diseases

[Mason Shaffer Foundation](#) – Malignant Infantile Osteopetrosis

[Massachusetts Biotechnology Council](#) – Multiple Rare Diseases

[Mast Cell Hope, Inc.](#) - Mast Cell Disease

[MEPAN.org](#) – MEPAN Syndrome

[Metaplastic Breast Cancer Global Alliance](#)

[Meningitis Foundation of America](#)

[MHE Coalition](#) – Multiple Hereditary Exostoses, Multiple Osteochondromatosis, Hereditary Multiple Exostoses

[Milo’s Journey Foundation](#) – Undiagnosed

[Minutes Matter](#) – Medium-chain acyl-CoA dehydrogenase deficiency (MCADD)

[Miracle Flights](#) – All Rare Diseases

[Miracle For Madison & Friends](#) – Spinal Muscular Atrophy

[Mission: Cure](#)

[Mission Massimo Foundation](#) – Leukodystrophy

[MitoAction](#) – Mitochondrial Disease

[MLD Foundation](#) – Metachromatic Leukodystrophy

[Moebius Syndrome Foundation](#) – China Doll Syndrome, Moebius Syndrome

[Mommies of Miracles](#) – Multiple Pediatric Rare Diseases

[Mo Songs for Kerry](#)– Li Fraumeni Syndrome

[MSA-AMS and World MSA Day](#)

[MSA NJ](#)– Multiple System Atrophy

[MSUD Family Support Group](#)

[MTM-CNM Family Connection, Inc.](#) – Myotubular and Centronuclear Myopathy

[Muscular Dystrophy Society Kenya](#) – Muscular Dystrophy

[Myasthenia Gravis Hope Foundation](#)– Myasthenia Gravis

[Myhre Syndrome Foundation](#) - Myhre Syndrome (SMAD4 Mutation)

[Myositis Support and Understanding Association](#) - Idiopathic Inflammatory Myopathies, Myositis

[Myotonic Dystrophy Foundation](#) – Myotonic Dystrophy

[Myrovlytis Trust](#) – Birt Hogg Dube Syndrome

[Narcolepsy Network](#) – Narcolepsy

[National Ataxia Foundation](#) - Ataxia

[National Foundation for Ectodermal Dysplasias](#) – Ectodermal Dysplasias

[National Gaucher Foundation](#) – Gaucher Disease

[National LeioMyoSarcoma Foundation](#) – LeioMyoSarcoma

[National Lymphedema Network](#) – Lymphedema-distichiasis syndrome, Hereditary lymphedema type II & other lymphademas

[National Marfan Foundation](#) – Marfan Syndrome

[National MPS Society](#) – Mucopolysaccharidoses

[National Niemann-Pick Disease Foundation](#) – Niemann Pick Disease

[National PKU Alliance](#) – Phenylketonuria

[National PKU News](#) – Phenylketonuria

[National Spasmodic Dysphonia Association](#) – Spasmodic Dysphonia, Laryngeal Dystonia

[National Stem Cell Foundation](#)

[National Tay-Sachs & Allied Disease Association](#) – Tay-Sachs, Canavan, Sandhoff, GM1 & related diseases

[NBIA Disorders Association](#) – Aceruloplasminemia, Neurodegeneration w/ Brain Iron Accumulation disorders, Hallervorden-Spatz Syndrome

[NEHI Research Foundation](#) – Neuroendocrine cell hyperplasia of infancy

[Neurofibromatosis Midwest](#) - Neurofibromatosis and Schwannomatosis

[Neurofibromatosis Network](#) – Neurofibromatosis Disease

[Neuromuscular Disease Foundation](#) – Neuromuscular Disease

[Nevus Outreach, Inc.](#) – Congenital Melanocytic Nevi and Related Disorders

[Newborn Coalition Foundation](#)– Newborn Screening

[New Zealand Organisation for Rare Disorders](#) – Multiple Rare Diseases

[New Zealand Pompe Network](#)

[Next Step Fund](#) – Life Threatening Diseases

[NF2BioSolutions](#) – Neurofibromatosis Type 2

[NGLY1 Foundation](#)– NGLY1 deficiency, N-glycanase deficiency

[Nicholas Volker One In A Billion Foundation](#)

[Niemann Pick Research Foundation](#) – Neimann Pick Disease

[Noah's Hope](#) – Batten Disease

[Nontuberculous Mycobacteria Info & Research](#) – Pulmonary Nontuberculous Mycobacterial

[Noonan Syndrome Foundation](#) – Noonan Syndrome

Noonan Syndrome Support Network – Noonan Syndrome

[NR2F1 Foundation](#) - Bosch Boonstra Schaaf optic atrophy syndrome

[NUBPL Foundation](#)

[Organic Acidemia Association](#) – Organic Acidemia

[Organization for Rare Diseases India](#) – Multiple Rare Diseases

[Orphan Disease Center](#)– Multiple Rare Diseases

[Osteopetrosis Society](#) – Osteopetrosis

[Our Odyssey](#) - All rare and chronic conditions for young adults 18-35

[\*\*Oxalosis and Hyperoxaluria Foundation\*\*](#) – Hyperoxaluria, Oxalosis

[\*\*Pachyonychia Congenita Project\*\*](#) – Pachyonychia Congenita

[\*\*PANDAS Network.org\*\*](#) – Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

Parent/Consumer Advocate for MS

[\*\*Parent Project Muscular Dystrophy\*\*](#) – Duchenne Muscular Dystrophy, Becker Muscular Dystrophy

[\*\*Pathways for Rare and Orphan Studies\*\*](#) (PROS) – Multiple Rare Diseases

[\*\*Patient Advocate Foundation\*\*](#) - General Support Organization

[\*\*PBCers Organization\*\*](#)

[\*\*PCDH19 Alliance\*\*](#) – PCDH19 Epilepsy

[\*\*Pediatric Brain Foundation\*\*](#) – Pediatric Neurologic Disorders

[\*\*Pediatric Hydrocephalus Foundation\*\*](#) – Hydrocephalus

[\*\*Perthes Kids Foundation\*\*](#) – Legg-Calvé-Perthes Disease

[\*\*Phelan-McDermid Syndrome Foundation\*\*](#) – 22Q13 Deletion Syndrome, Phelan-McDermid Syndrome

[\*\*Pheo Para Alliance\*\*](#) – Pheochromocytoma & Paraganglioma Diseases

[\*\*Pheo Para Project\*\*](#) – Pheochromocytoma & Paraganglioma

[\*\*Pitt Hopkins Research Foundation\*\*](#) – Pitt Hopkins

[\*\*Pituitary Network Association\*\*](#) – Pituitary Disorders

[\*\*PKD Foundation\*\*](#) – Polycystic Kidney Disease

[\*\*PKS Kids\*\*](#) – Pallister-Killian Syndrome

[\*\*PKS Kids Italia Onlus\*\*](#) – Pallister-Killian Syndrome

[\*\*Platelet Disorder Support Association\*\*](#) – Immune Thrombocytopenia

[\*\*PMG Awareness Organization, Inc.\*\*](#) – Polymicrogyria

[\*\*Pompe Foundation, India\*\*](#) – Pompe Disease

[\*\*Potocki-Lupski Syndrome Outreach Foundation, Inc\*\*](#) – Potocki-Lupski Syndrome

[\*\*Prader-Willi California Foundation\*\*](#) – Prader-Willi Syndrome

[\*\*Prader-Willi Syndrome Association\*\*](#) – Prader-Willi Syndrome

[\*\*PRISMS, Inc.\*\*](#) – Smith-Magenis Syndrome

[\*\*Project 8P\*\*](#) – Chromosome 8p

[\*\*Project Alive\*\*](#) - Hunter Syndrome or Mucopolysaccharidosis/MPS II

**PROS Foundation**

**Progeria Research Foundation** – Hutchinson-Gifford Progeria Syndrome

**Progressive Familial Intrahepatic Cholestasis Advocacy and Resource Network, Inc.** – Progressive Familial Intrahepatic Cholestasis

**PRP Alliance** – Pityriasis Rubra Pilaris

**PSC Community** – Primary Sclerosing Cholangitis

**PSC Partners** - Primary Sclerosing Cholangitis

**PTEN Hamartoma Tumor Syndrome Foundation**

**PTen World** – Cowden’s Syndrome

**Pulmonary Hypertension Association** – Pulmonary Hypertension

**PURA Syndrome Foundation** – PURA Syndrome

**Putting Rare Diseases Patients First!** - All Rare Diseases

**PVNH Support and Awareness** – Periventricular Nodular Heterotopia

**RACC- UK** – Periodic Fever Syndromes

**RareKC** – All Rare Diseases

**Rare & Undiagnosed Network** – Multiple Rare Diseases, Undiagnosed

**Rare Advocacy Movement** - All Rare Diseases

**Rare Disease Foundation** – Multiple Rare Diseases, Canada

**Rare Disease Ghana Initiative**– Multiple Rare Diseases, Ghana

**Rare Disease Kenya** – Multiple Rare Diseases, Kenya

**Rare Disease UK** – Multiple Rare Diseases

**Rare Disease Research and Support (RDRS) at Calvin University** - All Rare Diseases

**Rare Genomics Institute** – Multiple Rare Diseases

**Rare Kids Network, Inc.** - Pediatric Rare Diseases

**Rare New England** – Multiple Rare Diseases

**Rare Science** – Multiple Rare Diseases

**Rare Support** –

Rare United Network

**Raríssimas – Associação Nacional de Deficiências Mentais e Raras** – Multiple Rare Diseases, Portugal

**RASopathies Network USA** – RASopathy Syndromes

**RecurrentMeningitis Association** – Recurrent Meningitis



[Reflex Sympathetic Dystrophy Syndrome Association \(RSDSA\)](#) – Complex Regional Pain Syndrome

[Relapsing Polychondritis Awareness and Support Foundation](#) – Relapsing Polychondritis

[Remember the Girls](#) – X-linked Recessive Diseases

[Rettsyndrome.org](#) – Rett Syndrome

[Rhode Island Ehlers Danlos Syndrome Awareness and Support Group](#) – Ehlers Danlos Syndrome

[Ring 14 USA](#) – Chromosome 14 disorders

[RUNX1 Research Program](#) - RUNX1-Familial Platelet Disorder

[Ryan Wersten MIOP Foundation](#) – Malignant Infantile Osteopetrosis

[Salla Treatment and Research Foundation](#) – Salla Disease

[Sanfilippo Children’s Foundation](#) – SanFilippo

[Sanford Research](#) – Multiple Rare Diseases

[Sarcoidosis of Long Island](#) – Neurosarcoidosis, Sarcoidosis

[Sarcoma Foundation of America](#) – Sarcoma

[SATB2 Gene Foundation](#)– SATB2 Associated Syndrome

[SBS Cure Project](#) – Short Bowel Syndrome/Intestinal Failure

[SCAD Alliance](#) – Spontaneous Coronary Artery Dissection

[SCN2A Australia](#) - SCN2A

[SETBP1 Society](#) – SETBP1

[Shwachman-Diamond Syndrome Foundation](#) – Shwachman Diamond Syndrome

[Sick Cells](#) - Sickle Cell Disease

[Sickle Cell 101](#) – Sickle Cell Disease

[Sickle Cell Consortium](#) – Sickle Cell Disease

[Sing Me a Story](#) - General Support

[SLC6A1 Connect](#) – SLC6A1 (GAT1)

[Smith-Kingsmore Syndrome](#) – Smith-Kingsmore Syndrome

[SMS Research Foundation](#) – Smith-Magenis Syndrome

[Sofia Sees Hope, Inc.](#)

[Soft Bones Inc.](#) – Hypophosphatasia

[Soft Bones Canada](#) – Hypophosphatasia

[Spinal CSF Leak Foundation](#) – Cerebrospinal Fluid

[SPG15 Research Foundation](#) - SPG15

[SSADH Association](#)– Succinic Semialdehyde Dehydrogenase Deficiency

[St. Joseph's Children's Hospital](#), New Jersey - Multiple Rare Diseases

[Step by Stone Association](#)– Multiple Rare Diseases, Kenya

[Stone Soup Group](#) - All Rare Diseases

[Stop ALD Foundation](#) – X-linked adrenoleukodystrophy

[STXBP1 Disorders/Foundation](#)

[Super Kids: Mission Zero Inc.](#) – Epilepsy

[Super T's Mast Cell Foundation](#)-Mast Cell Activation Disorder

[Supporters of Families with Sickle Cell Disease, Inc.](#) – Sickle Cell Disease

[Support Organization for Trisomy 18, 13 & Related Diseases](#) – Trisomy 13 Disorder,  
Trisomy 18

[Sweet Nectar Society](#) – Multiple Rare Diseases

[Syndromes Without A Name USA](#) – Undiagnosed

[Tango2 Research Foundation](#) - Tango2

[Taylor's Tale](#) – Batten Disease

[T.E.A.M. 4 Travis](#) - Isolated Congenital Asplenia

[Team Impact](#)

[Team Jeffery for PF](#)

[Team Telomere](#) - Dyskeratosis Congenita

[Team Titin](#) – Titinopathies

[Teddington Trust](#) – Xeroderma Pigmentosum

[Tennessee PKU Foundation](#) - Phenylketonuria (PKU)

[The 22q Family Foundation](#) – 22q11.2 deletion, DiGeorge Syndrome, VCFS

[The AADC Research Trust](#)– Aromatic Amino Acid Decarboxylase Deficiency (AADC)

[The Aarskog Foundation](#)– Aarskog-Scott Syndrome

[The APS Type 1 Foundation](#)– Autoimmune Polyglandular Syndrome Type 1

The Avery's Fight Foundation

[The Bow Foundation](#)– GNAO1

[The Brain Recovery Project](#) – Multiple Rare Diseases

[The Burning Limb Foundation](#)

[The Calliope Joy Foundation](#)– Leukodystrophy

[The CHARGE Syndrome Foundation](#)– CHARGE Syndrome

[The Charles E. Holman Morgellons Disease Foundation](#)– Morgellons Disease

[The Chromosome 18 Registry & Research Society](#) – Chromosome 18 disorders

[The Cilly Cell Project](#) – Sickle Cell Disease

[The Coalition Against Pediatric Pain](#) – Multiple Pediatric Rare Diseases

[The Conley Cushing’s Disease Fund](#) – Cushing’s Disease

[The COPD Foundation](#) – Chronic Obstructive Pulmonary Disease

[The Cure Blau Syndrome Foundation](#) - Blau Syndrome

[The Cure Tay-Sachs Foundation](#)

[The Cute Syndrome](#) – PCDH19 Epilepsy and SCN8A Epilepsy

[The FAVA Foundation](#) – Fibro Adipose Vascular Anomaly

[The Genesis Foundation for Children](#) - Multiple Rare Diseases

[The Global Foundation for Peroxisomal Disorders](#) –Peroxisome Biogenesis Disorder, Zellweger Spectrum Disorder

[The Hypersomnia Foundation](#)– Idiopathic Hypersomnia

[The Jansen’s Foundation](#)– Jansen Type Metaphyseal Chondrodysplasia

[The LAMFoundation](#) – Lymphangiomyomatosis (LAM)

[The Life Raft Group](#) – Gastrointestinal Stromal Tumor (GIST)

[The Marfan Foundation](#) – Marfan Syndrome

[The Mastocytosis Society Inc](#) – Mastocytosis and Mast Cell Activation Disease

[The Mastocytosis Society Inc Southern California Support Group](#)

[The Metabolic Foundation](#) – Metabolic Disorders

[The Mitchell Thorp Foundation](#) - General Support Organization

[The Morgan Leary Vaughan Fund](#)

[The Mowat-Wilson Syndrome Foundation](#) – Mowat-Wilson Syndrome Foundation

[The Myositis Association](#) – Myositis

[The National Gaucher Foundation of Canada](#) - Gaucher

[The NICER Foundation](#) – Narcolepsy

[The Network of Tyrosinemia Advocates](#) – Tyrosinemia

[The Rare Genomes Project at the Broad Institute of MIT and Harvard](#)– Multiple Rare Diseases

[The Sickle Cell Foundation of Tennessee](#) - Sickle Cell

[The Snyder-Robinson Foundation](#) – Snyder-Robinson Syndrome

[The Speak Foundation](#) – Neuromuscular Diseases

[The Sturge-Weber Foundation](#) – Sturge-Weber Syndrome

[The TESS Foundation](#) – SLC13A5

[The Ultra Rare Disease Disorders and Disabilities Foundation](#)– Multiple Rare Diseases

[The Vision of Children Foundation](#) – Genetic Vision Disorders

[The WeHeal Foundation](#) - All Rare Diseases

[The Wiedemann-Steiner Syndrome Foundation](#)– Weidemann-Steiner Syndrome

[Theo's Village: The TBCK Foundation](#) - TBCK

[ThinkGenetic Foundation](#)– Multiple Rare Diseases

[Thisbe and Noah Scott Foundation, Inc.](#) – Pediatric Neurologic Disorders

[Timothy Syndromes Alliance](#) – Timothy Syndrome and CACNA1c mutations

[Translational Genomics Research Institute](#) – Multiple Rare Diseases

[Translational Pulmonary and Immunology Research Center](#) – Multiple Rare Diseases

[Traveling Awareness Bears](#) – Multiple Rare Diseases

[Trisomy 18 Foundation](#) – Trisomy 18, Edwards Syndrome

[TUBB3 Foundation](#)– TUBB3 Gene Mutations

[Tuberous Sclerosis Alliance](#)– Tuberous Sclerosis

[Tuberous Sclerosis Australia](#)

[Turner Syndrome Global Alliance](#) – Turner Syndrome

[Turner Syndrome Society of the United States](#) – Turner Syndrome

[U.R. Our Hope](#) – Undiagnosed

[United Leukodystrophy Foundation](#) – Leukodystrophies

[United Mitochondrial Disease Foundation](#) – Mitochondrial Encephalomyopathy

[Unique - Rare Chromosome Disorder Support Group](#) - Rare Chromosome and Single Gene Disorders

[University of Washington/Cystic Fibrosis Reproductive and Sexual Health Collaborative](#)

[Uplifting Athletes](#) - Umbrella Organization

[Usher 1F Collaborative, Inc](#) – Usher Syndrome Type 1F

[Usher Syndrome Coalition](#) – Usher Syndrome

[USP7 Families](#) – USP7 Related Diseases

[Utah Rare](#)– Multiple Rare Diseases

[Vancouver Acromegaly Support Group](#) – Gigantism, Acromegaly

[Vincent Gaynor & Sophia's Cure Foundation](#) – Spinal Muscular Atrophy

[VWM Families Foundation, Inc](#) – Vanishing White Matter Disease VWM/CACH

[Wake Up Narcolepsy](#) – Narcolepsy

[White Sutton Syndrome Foundation](#) – White Sutton Syndrome (WHSUS)

[Wilhelm Foundation](#) – Undiagnosed

[William E Proudford Sickle Cell Fund](#) – Sickle Cell Disease

[Williams Syndrome Association](#)– Williams Syndrome

[Wiskott Aldrich Foundation](#) – Wiskott-Aldrich Syndrome

[Wobbly Feet Foundation](#) – Ataxia-Telangiectasia

[Wylder Nation](#) – Lysosomal Diseases

[XLH Network](#) – X-Linked Hypophosphatemia

[XP Family Support Group](#) – Xeroderma Pigmentosum

[Zoe's Story](#) – CRMO/CNO

[ZTTK SON-Shine Foundation](#) - Zhu-Tokita-Takenouchi-Kim Syndrome