



The Global Genes RARE Foundation Alliance is made up of over 750 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 Breath Of Hope Foundation For NMO](#) - Neuromyelitis Optica

[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 Alternatives Foundation](#) - Adrenal Diseases

[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

[ALD Alliance](#) - ALD Adrenoleukodystrophy

[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

[ALS Ride For Life](#) - ALS

[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 Brain Tumor Association](#) - Brain Tumors

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

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

[American Porphyria Foundation](#) – Porphyria Disease

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

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

[Amyloidosis Research Consortium](#) – Amyloidosis

[Amyloidosis Support Groups Inc.](#) - Amyloidosis Support Groups throughout the United States

[AnCan\(formerly Answer Cancer Foundation\)](#) - Sarcoidosis, Renal Medullary Cancer, Male Breast Cancer

[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](#)
(ACPPM)– Pseudomyxoma Peritonei

[Aplastic Anemia & Myelodysplasia Association of Canada \(AAMAC\)](#) - Aplastic anemia, myelodysplastic syndrome and paroxysmal nocturnal hemoglobinuria

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

[APFED - American Partnership for Eosinophilic Disorders](#) - Eosinophilic related disorders

[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

[Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado \(APH\)](#) - Hemophilia

[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 Encephalitis Alliance](#) - Autoimmune Encephalitis

[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

[Axenfeld-Rieger Foundation](#) - Axenfeld-Rieger Syndrome

[AXYS](#) - One or more extra X and/or Y chromosomes

[Bardet Biedl Australia](#) - Bardet-Biedl Syndrome

[Bardet Biedl Families](#) - 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

[Bleeding Disorders Alliance Illinois](#) - Inherited Bleeding Disorders

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

[Bloom Syndrome Association](#) - Bloom Syndrome

[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

[Brandon's Battle Foundation For SKS Kids](#) - Smith Kingsmore Syndrome

[Brave Minds Project](#) - Brain and Brainstem Conditions

[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

[Care4ASH1L](#) - ASH1L related disorders

[CARES Foundation](#) – Congenital Adrenal Hyperplasia

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

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

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

[Cauda Equina Foundation, Inc.](#) - Cauda Equina Syndrome and associated disorders

[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

[Charcot-Marie-Tooth Association](#) - Charcot-Marie-Tooth

[Chelsea's Hope Lafora Children Fund](#) - Lafora Disease

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

[chILD Foundation](#) – Interstitial Lung Disease

[Child Neurology Foundation](#) – Childhood Neurological 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](#)

[CHOPS Syndrome Global](#) - Chops Syndrome

[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

[Coalition to Cure CHD2](#) - Find a cure for CHD2-Related Epilepsy and Autism

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

[COMBINEDBrain](#) - General Support Organization

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

[Congenital Hyperinsulinism International](#) – Congenital Hyperinsulinism

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

[Connor B. Judge Foundation](#) - NMO

[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

[CureARS](#) - Mitochondrial Aminoacyl-tRND Synthetase Research & Awareness

[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

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

[Cure Sanfilippo Foundation](#) – Sanfilippo Syndrome

[Cure SMA](#) - Spinal Muscular Atrophy

[Cure SMA Foundation of India](#) - Spinal Muscular Atrophy

[Cure Surf1](#) – SURF1 Leigh Syndrome

[Cure TBM](#)– TracheoBronchoMalacia

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

[Cure VCP Disease](#)

[CureGRIN](#) - GRIN

[CureLGMD2i Foundation](#)– Limb Girdle Muscular Dystrophy Type 2i

[CureSHANK](#) - Phelan-McDermid Syndrome and related SHANK3 disorders

[CureSPG50](#) - SPG50

[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](#)

[DDX3X Foundation](#) - General Support Organization

[debra of America](#) - Epidermolysis Bullosa

[Defeat MSA](#) - Multiple System Atrophy

[Dent Disease Foundation](#) - Dent Disease

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

[DHPS Foundation](#)

[DNA Checkup](#) – Recessive Genetic Disorders

[Dravet Syndrome Foundation](#) – Dravet Syndrome

[Dravet Syndrome Foundation Spain](#) - 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

[EBF3 HADDs Foundation](#) - EBF3-related HADDs

[The EHE Foundation](#) - Epithelioid Hemangioendothelioma

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

[EDSers United](#) – Ehlers Danlos Syndrome

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

[Ehlers-Danlos Society](#) - Global community focused on Ehlers-Danlos syndromes (EDS), hypermobility spectrum disorders (HSD) and related symptoms and conditions

[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 Alliance America](#) - Epilepsy, Seizure Disorders, Rare Epilepsies

[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

[Facial Pain Association](#) - Trigeminal Neuralgia

[FAM177A1](#)- Undiagnosed Community

[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 \(FDF\)](#) – McCune Albright syndrome, Fibrous dysplasia

[Fibrous Dysplasia Foundation FD/MAS Alliance](#) - Fibrous dysplasia/McCune Albright syndrome (FD/MAS Alliance)

[Fighting for Kaiden Foundation, Inc.](#) - Spinal Muscular Atrophy

[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

[ForeBatten Foundation](#) - Juvenile Batten Disease

[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

[Foundation to Fight H-abc](#) - H-ABC

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

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

[Fundacion Huntington Puerto Rico](#) - Huntington

[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

[Gaucher Community Alliance](#) - Gaucher

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

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

[Genesic Nonprofit Organization, Incorporated](#) - Sickle Cell

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

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

[Genetic Epilepsy Team Australia](#) - Genetic Epilepsies

[Glut1 Deficiency Foundation](#) - Glut1 Deficiency

[Global DARE Foundation](#) - Refsum Disease

[Global Hydranencephaly Foundation](#) – Hydranencephaly

[Global Liver Institute](#) - Liver Diseases

[Global Pediatrics MDS Initiative](#) - Global Pediatric MDS Initiative

[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

[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.

[Hope Life International Gambia](#)- Pituitary, Adrenal, Achalasia, and Tuberculosis (TB)

[Hope Life Support & Empowerment \(HLSE\)- Nigeria](#) - Hope Life Support and Empowerment- Nigeria

[Hope Life Support and Empowerment \(HLSE\) Sierra Leone](#) - Hope Life Support and Empowerment - Sierra Leone

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

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

[HudsonAlpha Institute for Biotechnology](#)

[Humans with Knobloch Syndrome](#) - Knobloch Syndrome

[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

[iDefine](#) - Kleefstra Syndrome

[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

[IndoUSrare](#) - General Support Organization

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

[Instituto Vidas Raras \(Rare Lives Institute\)](#) - Brazillian umbrella organization for rare diseases

[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 Prader-Willi Syndrome Organisation \(IPWSO\)](#) - Prader-Willi Syndrome

[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

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

[Jett Foundation](#) – Duchenne Muscular Dystrophy

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

[Jordan's Guardian Angels](#) - Jordan's Syndrome; Genetic misspelling of the genes PPP2R5D, PPP2R1A, PPP2R5C

[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](#)

[KIF4A Foundation](#) - KIF4A Associated Neurodevelopmental Syndrome (KANS)

[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

[Lightning and Love Foundation](#) - Advocacy and research into THAP12 mutation related disease

[Lily’s List](#) - Pediatric patients with a need for hospital-to-home health nursing

[Little Zebra Fund](#) - Undiagnosed & General Support Organization

[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

[Love Never Sinks](#) - General Support Organization

[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

[MacPac Foundation](#) - Hypomyelination with brainstem and spinal cord involvement and leg spasticity (HBSL)

[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

[**MCT8-AHDS Foundation**](#) - MCT8 Deficiency aka Allen Herndon Dudley Syndrome

[**MECP2 Duplication Foundation**](#) - MECP2 Duplication Syndrome

[**Meg's Miracles**](#) - Childhood / Pediatric and Adult Onset SPS

[**MEPAN.org**](#) – MEPAN Syndrome

[**Metaplastic Breast Cancer Global Alliance**](#)

[**Meningitis Foundation of America**](#)

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

[**Mickie's Miracles**](#) - Infantile Spasms, Pediatric Epilepsy

[**Miles for CF**](#) - Cystic Fibrosis

[**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

[**Mississippi Metabolics Foundation**](#) - Rare Genetic Metabolic Disorders / IEMs

[**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

[**Moyamoya Foundation Co**](#) - Moyamoya Disease

[**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 Family Foundation**](#) Muscular Dystrophy, Neuromuscular Diseases

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

[**My PKU Awareness Foundation**](#) - PKU

[**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 Fragile X Foundation**](#) - National Fragile X Foundation

[National Gaucher Foundation](#) – Gaucher Disease

[National Hemophilia Foundation](#) - Hemophilia

[National LeioMyoSarcoma Foundation](#) – LeioMyoSarcoma

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

[National Marfan Foundation](#) – Marfan Syndrome

[National MPS Society](#) – Mucopolysaccharidoses

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

[National Organization of Disorders of the Corpus Callosum \(NODCC\)](#) - Disorders of the Corpus Callosum

[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

[NephCure Kidney International](#) - Rare Forms of Nephrotic Syndrome

[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-Hope 4 Bridget Foundation](#) – 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](#)

[One Rare](#) - Serving young adults with rare and chronic conditions

[Organic Acidemia Association](#) – Organic Acidemia

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

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

[Osteopetrosis Society](#) – Osteopetrosis

[Ostomy 2-1-1 Inc.](#) - Ostomy, Short Gut, Short Bowel

[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

[Pathways To Trust](#) - General Support Organization, current focus Sickle Cell Disease

[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

[Pericarditis Alliance](#) - Pericarditis Alliance

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

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

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

[PHIP Kids \(Chung-Jansen Syndrome\)](#) - Chung-Jansen Syndrome

[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

[PMP Pals Network](#) - Pseudomyxoma Peritonei

[Pompe Alliance](#) - Pompe Disease

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

[Pompe Warrior Foundation](#) - Pompe Disease

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

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

[Prader-Willi Syndrome Association](#) | USA – 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

[RareABILITY](#) - Hosts empowerment workshops and crafting activities for people of varying abilities

[Rare Advocacy Movement](#) - All Rare Diseases

[Rare Disease Foundation](#) – Multiple Rare Diseases, Canada

[Rare Disease Ghana Initiative](#)– Multiple Rare Diseases, Ghana

[Rare disease Innovations Institute](#) - Multiple Rare Diseases

[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

[Rare Trait Hope Fund](#) - Aspartylglucosaminuria

[Rare Village Foundation](#) - General Support Organization for several rare disorders

[RARE-X](#) - Rare Disease Data Collection Platform (Diagnosed and Undiagnosed)

[Raríssimas – Associação Nacional de Deficiências Mentais e Raras](#) – Multiple Rare Diseases, Portugal

[RASopathies Network USA](#) – RASopathy Syndromes

[Raymond A. Wood Foundation](#) - Hypothalamic-Pituitary Brain Tumor Survivors

[RecurrentMeningitis Association](#) – Recurrent Meningitis

[Redmoon Project, Inc](#) - Lifting Sickle Cell Warriors Across The World

[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

[Save Sight Now](#) - Usher Syndrome Type 1B

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

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

[Scheuermann's Disease Fund](#) - Scheuermann's Disease Fund

[SCN2A Australia](#) - SCN2A

[SETBP1 Society](#) – SETBP1

[Shwachman-Diamond Syndrome Alliance](#) - Shwachman-Diamond Syndrome

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

[Sick Cells](#) - Sickle Cell Disease

[Sickle Cell Red](#) - Sickle Cell Disease

[Sickle Cell Association of Texas Mark Thomas Foundation](#) - Sickle Cell General Support Organization

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

[Sickle Cell and Young Stroke Survivors](#) - Sickle Cell Disease and Others

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

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

[Sisters' Hope Foundation](#) - Adult Onset Leukoencephalopathy with Axonal Spheroids and Pigmented Glia

[SLC6A1 Connect](#) – SLC6A1 (GAT1)

[SMC1A Foundation](#) - SMC1A Loss-of-function Epilepsy

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

[SMA - Bhutan](#) - Spinal Muscular Atrophy - Bhutan

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

[Sofia Sees Hope, Inc.](#)

[Soft Bones Inc.](#) – Hypophosphatasia

[Soft Bones Canada](#) – Hypophosphatasia

[Sophies Hope Foundation Inc](#) - Glycogen Storage Disease Type 1b

[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

[Stories Matter Foundation](#) - General Support Organization

[Stronger Than Sarcoidosis](#) - Sarcoidosis

[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

[SynGap Research Fund](#) - SynGap

[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 Joseph](#) - Duchenne

[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 Akari Foundation](#) - Duchenne Muscular Dystrophy

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

[The ARM Foundation](#) - The ARM Foundation

[The Avery’s Fight Foundation](#) - Homozygous Familial Hypercholesterolemia (HoFH)

[The Avalon Foundation](#) - Hypophosphatasia, growing into General Support Organization

[The Boston International Turner Syndrome Summit](#) - Turner Syndrome

[The Bow Foundation](#)- GNAO1

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

[The Burning Limb Foundation](#)

[The Calliope Joy Foundation](#)- Leukodystrophy

[The Champ Foundation](#) - Single large scale mitochondrial DNA deletion syndromes (Pearson syndrome)

[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 Dent Disease Foundation](#) - Dent Disease

[The DRESS Syndrome Foundation](#) - Drug Reaction with Eosinophilia and Systemic Symptoms

[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 Menkes Foundation](#) - General Support Organization

[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 Sumaira Foundation for NMO](#) - Neuromyelitis Optica Spectrum Disorder

[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 Syndrome 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

[USTMA Consortium](#) - Thrombotic Microangiopathies

[Utah Rare](#) – Multiple Rare Diseases

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

[VHL Alliance](#) - VHL

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

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

[**Wake Up Narcolepsy**](#) – Narcolepsy

[**WeCareJourney**](#) - Spinal Muscular Atrophy (SMA)

[**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

[**Wilson Disease Association**](#) - Wilsons Disease

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

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

[**WonderFIL Smiles**](#) - General Support Organization

[**Wylder Nation**](#) – Lysosomal Diseases

[**Xia-Gibbs Society, Inc.**](#) - Xia-Gibbs Syndrome

[**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