The Global Genes RARE Foundation Alliance is made up of over 600 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 (PIDD), 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 Adrenoleukodystophy
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 (ACPMP)– 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
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

AsociaciÃn PuertorriqueÃa 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
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 Vitreopothy (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
Crafting4aCause - Hosts empowerment workshops and crafting activities for people of varying abilities
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
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 FOXG1 Foundation – FOXG1 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 – Hypomagnesmia with Secondary Hypocalcimia (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
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

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
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 lymphademas

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 – Pheochromochtoma & 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
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 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
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 – Lymphangioleiomyomatosis (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