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 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 (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

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 Polcystic 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-Assiciated 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 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

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

CureSPG50 - SPG50

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 – Friedreichs 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 FOXG1 Foundation – FOXG1 gene mutation

International Pemphignus & 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 – 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

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 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 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 – Pheochromochtoma & 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

PMP Pals Network - Pseudomyxoma Peritonei

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

Save Sight Now - Usher Syndrome Type 1B

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 and Young Stroke Survivors - Sickle Cell Disease and Others

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
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 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 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 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 – 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 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