FOUNDATION ALLIANCE

Global Genes RARE Foundation Alliance is made up of more than 500 disease foundations that are committed to collaborating with Global Genes and other nonprofit foundations in order to create a stronger, collective voice in the rare disease community.

- #11q Research & Resource Group – Jacobsen Syndrome, 11q Chromosome
- 1p36 Deletion Support & Awareness – 1p36 Deletion Syndrome
- 4p- Support Group – Wolf-Hirschhorn Syndrome and related 4p conditions
- 5p-Society– 5p- Syndrome, Cat Cry Syndrome, Cri du Chat Syndrome
- A Foundation Building Strength for Nemaline Myopathy – Nemaline Myopathy
- Aaron's Ohtahara – Ohtahara Syndrome
- Acid Maltase Deficiency Association– Acid Maltase Deficiency, Pompe's Disease
- Acromegaly Community – Acromegaly and Gigantism
- 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 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)

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

APS Type 1 Foundation – APS Type 1 (APECED)

Arachnoiditis Society for Awareness and Prevention – Arachnoiditis

Arachnoiditis and Chronic Meningitis Collaborative Research Network

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

Bcureful – Tuberous Sclerosis Complex

Beautiful You MRKH Foundation – Mayer-Rokitansky-Küster-Hauser 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

Bohring-Opitz Syndrome Foundation, Inc. – Bohring-Opitz Syndrome

Bold Lips For Sickle Cell – Sickle Cell Disease

Boomer Esiason Foundation – Cystic Fibrosis

Born a Hero – Pfeiffer Syndrome

BPAN Warriors– Beta-Propeller Protein-Associated Neurodegeneration

BRBN Alliance – Blue Rubber Bleb Nevus

Bridge the Gap – SYNGAP1

Bronchiectasis Foundation – Bronchiectasis

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 Marfan Association – Marfan Syndrome, Loeys-Dietz Syndrome, ACTA2, Familial Aortic Aneurysm, Familial Ectopia Lentis disorders

Canadian MPS Society-Mucopolysaccharide and Related Diseases

Canadian Organization for Rare Disorders – Multiple Rare Diseases
Canadian PKU & Allied Disorders – Phenylketonuria
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
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
CIDP Will Not Win – Chronic inflammatory demyelinating polyneuropathy (CIDP)
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
Complex Child E-Magazine – Multiple Pediatric Rare Diseases
Congenital Hyperinsulinism International – Congenital Hyperinsulinism
Connecting Families Urea Cycle Disorders Foundation
Coriell Institute for Medical Research – Multiple Rare Diseases
Cornelia de Lange Syndrome Foundation – Cornelia de Lange Syndrome
Cortical Foundation – Cortical Malformations
Costello Syndrome Family Network – Costello Syndrome
Crohn's Disease Warrior Patrol – Crohn's Disease, Ulcerative Colitis
CPRS Forum– Complex Regional Pain Syndrome
CSNK2A1 Foundation– Okur-Chung Neurodevelopmental Syndrome (OCNDS)
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 Surf1 – SURF1 Leigh Syndrome
Cure TBM– TracheoBronchoMalacia
Cures Within Reach – Multiple Rare Diseases
Cure VCP Disease
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 Reproductive and Sexual Health Collaborative – Cystic Fibrosis
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
Dempster Family Foundation – 22q11.2 deletion, DiGeorge Syndrome, VCFS
DPHS Foundation
DNA Checkup – Recessive Genetic Disorders
Donors Cure
Dravet Syndrome Foundation – Dravet Syndrome
Dup15q Alliance – Chromosome 15q Duplication Syndrome
DYRK1A Community – DYRK1A
Dyskeratosis Congenita Outreach – Dyskeratosis Congenita
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
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
Fibromadness– Fibromyalgia
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 – Ichthyosis Skin Disease

FMD Chat – Fibromuscular dysplasia

FMF & AID Global Association – Familial Mediterranean Fever & Autoinflammatory Diseases

FIRST: Foundation for Ichthyosis & Related Skin Types – Skin Diseases, Ichthyosis

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

Garrett the Grand – Batten Disease

GBS/CIDP Foundation International – Guillain-Barré Syndrome, Chronic Inflammatory Demyelinating Polyneuropathy

Gene Giraffe Project – Multiple Rare Diseases

Genetic Alliance UK – Multiple Rare Diseases

Global Hydranencephaly Foundation – Hydranencephaly

GNE Myopathy International – GNE Myopathy, Hereditary Inclusion Body Myopathy , HIBM

Grey's Gift Memorial Foundation – Globoid Cell Leukodystrophy, Krabbe Disease, Newborn Screening

GRIN2B Foundation

Grupo De Estudos Doencas Raras –Multiple Rare Diseases, Brazil

Guardian Hands Foundation– Multiple Rare Dieases

Gwendolyn Strong Foundation – Spinal Muscular Atrophy

Hadley Hope Fund – Niemann-Pick Type C disease

HAE Canada – Hereditary Angioedema

Hannah's Hope Fund – Giant Axonal Neuropathy

Harmony 4 Hope – Multiple Rare Diseases

Harry's Fund – Cri du Chat syndrome

HCU Network America

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

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 4 Tyler and Luke – Med 23 gene defect

HPS Network – Hermansky-Pudlak Syndrome

HSAN1E Society – Hereditary Sensory and Autonomic Neuropathy, Type 1E

HudsonAlpha Institute for Biotechnology

Hunter Evan Short Gut Foundation – Short Gut 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

Idic15 Canada– Chromosome 15q11.2-13.1 Duplication Syndrome

I Have IIH Foundation – Idiopathic Intracranial Hypertension

IHope Foundation – Intractanical Hypertension

Incontinentia Pigmenti Inernational 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 Autoimmune and Autoinflammatory Arthritis

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

ISMRD The International Advocate for Glycoprotein Storage Diseases – Glycogen Storage Disease

Jamie's Dream Team – Multiple Rare Diseases

Jansen's Foundation – Jansen's Disease

Jett Foundation – Duchenne Muscular Dystrophy

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

Jonah's Just Begun- Foundation to Cure Sanfilippo– Sanfilippo

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

Julia and Maya Clark Foundation– Mitochondrial disorders and CDKL5

Kabuki Syndrome USA –Kabuki syndrome

KCNQ2 Cure – KCNQ2

KIF1A.org

Klippel-Feil Syndrome Alliance – Klippel-Feil Syndrome

Klippel-Feil Syndrome Freedom – Klippel-Feil Syndrome

Kneading Hope – Multiple Rare Diseases

KrabbeConnect – Krabbe

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
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
Marrow For Life, Inc. – Stem Cell Treatments for Rare Diseases
Mason Shaffer Foundation – Malignant Infantile Osteopetrosis
Massachusetts Biotechnology Council – Multiple Rare Diseases
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
Mitchell Thorp Foundation– Multiple Rare Diseases
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

Myotonic Dystrophy Foundation – Myotonic Dystrophy

Myrovlytis Trust – Birt Hogg Dube Syndrome

Narcolepsy Network – Narcolepsy

National Foundation for Ectodermal Dysplasias – Ectodermal Dysplasias

National Gaucher Foundation – Gaucher Disease

National LeioMyoSarcoma Foundation – LeioMyoSarcoma

National Lymphedema Network – Lymphedema-distichiasis syndrome, Hereditary lymphedema type II & other lymphademas

National Marfan Foundation – Marfan Syndrome

National MPS Society – Mucopolysaccharidoses

National Niemann-Pick Disease Foundation – Niemann Pick Disease

National PKU Alliance – Phenylketonuria

National PKU News – Phenylketonuria

National Spasmodic Dysphonia Association – Spasmodic Dysphonia, Laryngeal Dystonia

National Stem Cell Foundation

National Tay-Sachs & Allied Disease Association – Tay-Sachs, Canavan, Sandhoff, GM1 & related diseases

NBIA Disorders Association – Aceruloplasminemia, Neurodegeneration w/ Brain Iron Accumulation disorders, Hallervorden-Spatz Syndrome

NEHI Research Foundation– Neuroendocrine cell hyperplasia of infancy

Neurofibromatosis 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

NUBPL Foundation

Organic Acidemia Association – Organic Acidemia

Organization for Rare Diseases India – Multiple Rare Diseases

Orphan Disease Center– Multiple Rare Diseases

Osteopetrosis Society – Osteopetrosis

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

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

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

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

PTEN Hamartoma Tumor Syndrome Foundation

PTen World – Cowden's Syndrome

Pulmonary Hypertension Association – Pulmonary Hypertension

PURA Syndrome Foundation – PURA Syndrome

PVNH Support and Awareness – Periventricular Nodular Heterotopia

RACC- UK – Periodic Fever Syndromes

RareKC – All Rare Diseases

Rare & Undiagnosed Network – Multiple Rare Diseases, Undiagnosed

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 United Foundation – Multiple Rare Diseases

Rare Genomics Institute – Multiple 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

Russell-Silver Support Network – Russell-Silver Syndrome, Small Gestational Age

Ryan Wersten MIOP Foundation – Malignant Infantile Osteopetrosis

Salla Treatment and Research Foundation – Salla Disease

Sanfilippo Children's Foundation – SanFilippo

Sanfilippo Foundation for Children – SanFilippo

Sanford Research – Multiple Rare Diseases

Sarcoidosis of Long Island – Neurosarcoidosis, Sarcoidosis

Sarcoma Foundation of America – Sarcoma

SATB2 Gene Foundation– SATB2 Associated Syndrome

Saving Case and Friends – Hunter Syndrome, Mucopolysaccharidosis/MPS II

SBS Cure Project – Short Bowel Syndrome/Intestinal Failure

SCAD Alliance – Spontaneous Coronary Artery Dissection

SETBP1 Society – SETBP1

Shwachman-Diamond Syndrome Foundation – Shwachman Diamond Syndrome

Sickle Cell 101 – Sickle Cell Disease

Sickle Cell Consortium – Sickle Cell Disease

SLC6A1 Connect – SLC6A1 (GAT1)

Smith-Kingsmore Syndrome – Smith-Kingsmore Syndrome

SMS Research Foundation – Smith-Magenis Syndrome

Snappin' Ministries – Multiple Rare Diseases

Sofia Sees Hope, Inc.

Soft Bones Inc. – Hypophosphatasia

Soft Bones Canada – Hypophosphatasia

Spinal CSF Leak Foundation – Cerebrospinal Fluid

SSADH Association– Succinic Semialdehyde Dehydrogenase Deficiency

Step by Stone Association– Multiple Rare Diseases, Kenya

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

Supporting Families with Koolen-deVries Syndrome – Koolen – deVries Syndrome, C17q21.31 microdeletion syndrome

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

Taylor's Tale – Batten Disease

Team Impact

Team Jeffery for PF

Team Titin – Titinopathies

Teddington Trust – Xeroderma Pigmentosum

The 22q 11 Ireland support group – 22q11.2 deletion syndrome

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

The APS Type 1 Foundation– Autoimmune Polyglandular Syndrome Type 1

The Aarskog Foundation– Aarskog-Scott Syndrome

The Avery's Fight Foundation

The Bow Foundation– GNAO1

The Brain Recovery Project – Multiple Rare Diseases

The Burning Limb Foundation

The Calliope Joy Foundation– Leukodystrophy

The CHARGE Syndrome Foundation– CHARGE Syndrome

The Charles E. Holman Morgellons Disease Foundation– Morgellons Disease

The Chromosome 18 Registry & Research Society – Chromosome 18 disorders

The Cilly Cell Project – Sickle Cell Disease

The Coalition Against Pediatric Pain – Multiple Pediatric Rare Diseases

The Conley Cushing's Disease Fund – Cushing's Disease

The COPD Foundation – Chronic Obstructive Pulmonary Disease

The Cure Tay-Sachs Foundation

The Cute Syndrome – PCDH19 Epilepsy and SCN8A Epilepsy

The Double Hit Lymphoma Foundation – Double Hit Lymphoma

The FAVA Foundation – Fibro Adipose Vascular Anomaly

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 Morgan Leary Vaughan Fund
The Mowat-Wilson Syndrome Foundation – Mowat-Wilson Syndrome Foundation
The Myositis Association – Myositis
The National Gaucher Foundation of Canada – Gaucher Disease
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 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 Wiedemann-Steiner Syndrome Foundation– Weidemann-Steiner Syndrome
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
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
Williams Syndrome Changing Lives Foundation – Williams syndrome
Williams Syndrome Family of Hope – 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