



**The Global Advocacy Alliance is made up of foundations and organizations 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.**

<b>Organization</b>	<b>Website</b>	<b>Rare Disease Served</b>
ACMCRN Arachnoiditis & Chronic Meningitis Collaborative Research Network	<a href="http://www.acmcrn.org">www.acmcrn.org</a>	Arachnoiditis
Adult Polyglucosan Body Disease Research Foundation	<a href="http://www.APBDRF.org">www.APBDRF.org</a>	Adult Polyglucosan Body Disease
Alaafia Women	<a href="http://strengthinsicklecell.com/">http://strengthinsicklecell.com/</a>	Sickle Cell
All GOD's Children	n/a	General
Angelman Syndrome Foundation	<a href="https://www.angelman.org/">https://www.angelman.org/</a>	Angelman Syndrome
ASXL Rare Research Endowment Foundation	<a href="http://www.arrefoundation.org">www.arrefoundation.org</a>	Asxl-Related Disorders (Bohring-Opitz Syndrome/Asxl1, Shashi-Pena Syndrome/Asxl2, Bainbridge-Ropers Syndrome/Asxl3)
Ataxia and me	<a href="http://www.ataxia-and-me.org">www.ataxia-and-me.org</a>	Ataxia, Associated Rare Disease And Movement Disorders
Autoimmune Registry Inc.	<a href="https://www.autoimmuneregistry.org/">https://www.autoimmuneregistry.org/</a>	All Autoimmune And Autoinflammatory Diseases
Avery's Hope	<a href="https://averys-hope.org/">https://averys-hope.org/</a>	Rare, Ultra Rare And Undiagnosed Pediatric Gi Diseases
Beautiful You MRKH Foundation	<a href="http://www.beautifulyourmrkh.org">www.beautifulyourmrkh.org</a>	Mayer-Rokitansky-Küster-Hauser Syndrome
Beck-Fahrner Syndrome Foundation	<a href="http://www.beckfahrner.org">www.beckfahrner.org</a>	Beck-Fahrner Syndrome
Breathe Support Network	<a href="http://www.breathesupport.org">www.breathesupport.org</a>	Support Patients And Families Affected By Pulmonary Fibrosis
CACNA1A Foundation	<a href="https://www.cacna1a.org/">https://www.cacna1a.org/</a>	Cacna1A-Related Diseases, Epilepsy, Ataxia (Episodic Ataxia Type 2, Spinocerebellar Ataxia Type 6, Congenital Ataxia), Hemiplegic Migraines, Nystagmus
Canadian Association of Pompe	<a href="https://www.pompecanada.com/">https://www.pompecanada.com/</a>	Pompe Disease
Care-for-Rare America Inc	<a href="https://care-for-rare-america.org/">https://care-for-rare-america.org/</a>	Primary Immunodeficiencies (Pid), Very Early Onset Inflammatory Bowel Disease, And Other Rare Diseases Of The Blood, Bone Marrow, And Immune System.
Care4ASH1L	<a href="https://care4ash1l.com">https://care4ash1l.com</a>	Ash1L Related Disorders
Caring Hands Sarcoidosis Foundation	<a href="https://www.sarcoidnetwork.org/">https://www.sarcoidnetwork.org /</a>	Sarcoidosis
CDG Canada	<a href="https://canadacdg.com/">https://canadacdg.com/</a>	Congenital Disorders Of Glycosylation

		(Cdg)
Charcot-Marie-Tooth Association	<a href="http://www.cmtausa.org">www.cmtausa.org</a>	Charcot-Marie-Tooth (Cmt) Disease
Children's Adaptability Network	<a href="https://childrensadaptabilitynetwork.org/">https://childrensadaptabilitynetwork.org/</a>	Any/All - Our Son Had Atrx Syndrome
CLOVES Syndrome Community	<a href="https://clovessyndrome.org/">https://clovessyndrome.org/</a>	Cloves Syndrome And Pik3Ca Related Overgrowth
Congenital Hyperinsulinism International	<a href="https://congenitalhi.org/">https://congenitalhi.org/</a>	Congenital Hyperinsulinism
Cookies4Cures	<a href="http://www.cookies4cures.com">www.cookies4cures.com</a>	Mcto, Sma, Veds, Pans, Batten, Slc6A1, Hae
Cure SZT2	<a href="https://www.szt2.org/">https://www.szt2.org/</a>	Szt2
Cystinosis Research Network	<a href="http://www.cystinosis.org">www.cystinosis.org</a>	Cystinosis
Danny's Dose Alliance	<a href="http://www.dannysdose.com">www.dannysdose.com</a>	Als, Ald, Adrenal Insufficiency, Complex Diabetes, Bleeding Disorders, Pha, Ucd, Sickle Cell, Epilepsy, Mcadd And More
Dreamsickle Kids Foundation, Inc	<a href="http://www.dreamsicklekids.org">www.dreamsicklekids.org</a>	Sickle Cell Disease And All Rare Diseases
DYRK1A Syndrome US & International Association	<a href="http://www.dyrk1a.org">www.dyrk1a.org</a>	Dyrk1A Syndrome
Eric's Journey Foundation	<a href="https://www.ericjourney.org/">https://www.ericjourney.org/</a>	Hemophagocytic Lymphohistiocytosis (Hlh), Still'S Disease, All Rare Diseases
Eyes on the Future	<a href="http://www.vickyseyes.org">www.vickyseyes.org</a>	Inherited Retina Dystrophy Linked To Gene Rdh12
Fabry Support & Information Group	<a href="http://www.fabry.org">www.fabry.org</a>	Fabry Disease
FamilieSCN2A Foundation	<a href="http://www.scn2a.org">www.scn2a.org</a>	Scn2A
Fibrous Dysplasia Foundation dba FD/MAS Alliance	<a href="https://fdmasalliance.org/">https://fdmasalliance.org/</a>	Fibrous Dysplasia, Mccune-Albright Syndrome
Foundation for Sarcoidosis Research	<a href="http://www.stopsarcodosis.org">www.stopsarcodosis.org</a>	Sarcoidosis
Fundación RHYO	<a href="http://fundacionrhyo.org/">http://fundacionrhyo.org/</a>	Hipertensión Pulmonar, Fibrosis Pulmonar, Esclerosis Multiplique, Edema Macular
Gaucher Community Alliance	<a href="http://www.gauchercommunity.org">www.gauchercommunity.org</a>	Gaucher
Girls Chronically Rock	<a href="https://girlschronicallyrock.com/">https://girlschronicallyrock.com/</a>	Muscular Dystrophy
Global Liver Institute	<a href="https://www.globalliver.org/">https://www.globalliver.org/</a>	All Liver Diseases. Our Pediatric And Rare Team Would Be Interacting Member.
GRIN2B Foundation	<a href="http://www.grin2b.org">www.grin2b.org</a>	Grin2B Related Neurodevelopmental Disorder
HCU Network America	<a href="https://hcunetworkamerica.org">https://hcunetworkamerica.org</a>	Homocystinuria, Classical Homocystinuria (Cystathionine Beta Synthase), Cobalamin C, Cobalamin D, Cobalamin E, Cobalamin F, Cobalamin G, Cobalamin J, Cobalamin X, Severe Mthfr
HypoPARathyroidism Association, Inc	<a href="http://www.hypopara.org">www.hypopara.org</a>	Hypoparathyroidism, Surgical, Non Surgical- Genetic, Autoimmune, Idiopathic
I am in PAIN and yet I LAUGH	n/a	Pidd, Ehlers-Danlos Syndrome, Pots, Gastroparesis, & All Other Rare Diseases
Indian Prader Willi Syndrome Association India	<a href="http://www.ipwsa.com/">http://www.ipwsa.com/</a>	Prader Willi Syndrome, Chromosome 15(Q11-Q13)
Indo US Organization for Rare Diseases (IndoUSrare)	<a href="https://www.indousrare.org/">https://www.indousrare.org/</a>	Disease Agnostic (All Rare Diseases)
Inspire Medical Communications, LCC	<a href="https://www.inspiremedicalcommunications.com/">https://www.inspiremedicalcommunications.com/</a>	Disease Agnostic (All Rare Diseases)
International Foundation for CDKL5	<a href="http://www.cdkl5.com">www.cdkl5.com</a>	Cdkl5 Disorders

Research		
International Pain Foundation	<a href="http://www.internationalpain.org">www.internationalpain.org</a>	Diseases Causing Chronic Pain
International Pemphigus Pemphigoid Foundation	<a href="https://www.pemphigus.org/">https://www.pemphigus.org/</a>	Pemphigus And Pemphigoid (Includes All Sub-Variants)
International Prader-Willi Syndrome Organisation	<a href="https://ipwso.org/">https://ipwso.org/</a>	Prader-Willi Syndrome
Jamal's Helping Hands	<a href="http://www.jamalshelpinghands.org">www.jamalshelpinghands.org</a>	Rare Disease
KBG Foundation	<a href="http://www.kbgfoundation.com">www.kbgfoundation.com</a>	Kbg Syndrome
KBG Syndrome Association	n/a	Kbg Syndrome- Ankrd11
Koolen-de Vries Syndrome Foundation	<a href="http://www.kdvsfoundation.org">www.kdvsfoundation.org</a>	Koolen-De Vries Syndrome Foundation
LGMD Awareness Foundation, Inc.	<a href="https://www.lgmd-info.org/">https://www.lgmd-info.org/</a>	30+ Subtypes Of Limb-Girdle Muscular Dystrophy (Lgmd)
Lightning and Love Foundation	<a href="http://www.lightningandlove.org">www.lightningandlove.org</a>	Thap12 Recessive Genetic Disease
lymphangiomas & gorham's disease alliance	<a href="https://www.lgdalliance.org/">https://www.lgdalliance.org/</a>	Complex Lymphatic Anomalies Including Generalized Lymphatic Anomaly, Gorham Stout Disease, Kaposiform Lymphangiomas And Central Conducting Lymphatic Anomaly
Malan Syndrome Foundation	<a href="https://www.malansyndrome.org/">https://www.malansyndrome.org/</a>	Malan Syndrome
MarylandRARE	<a href="https://marylandrare.org/">https://marylandrare.org/</a>	Disease Agnostic (All Rare Diseases)
Meg's Miracles	<a href="http://www.megsmiracles.org">www.megsmiracles.org</a>	Stiff Person Syndrome (Pediatric And Adult Onset)
Melanin Children Matter Inc	<a href="https://melaninchildrenmatter.org/">https://melaninchildrenmatter.org/</a>	Sptlc2 Gene Mutation/ Pediatric Als
Mesothelioma Applied Research Foundation	<a href="http://www.curemeso.org">www.curemeso.org</a>	Mesothelioma
Mission: Cure	<a href="https://mission-cure.org/">https://mission-cure.org/</a>	Chronic And Recurrent Acute Pancreatitis
Mississippi Metabolics Foundation	<a href="https://www.msmetabolics.org/">https://www.msmetabolics.org/</a>	Genetic Metabolic Disorders/Inborn Errors Of Metabolism (Iem).
MLD Foundation	<a href="https://MLDfoundation.org">https://MLDfoundation.org</a>	Metachromatic Leukodystrophy
My Little Sunshine Foundation	<a href="http://www.mylittlesunshine.org">www.mylittlesunshine.org</a>	Infertility And Cancer
NBIA Disorders Association	<a href="http://www.NBIAdisorders.org">www.NBIAdisorders.org</a>	Neurodegeneration With Brain Iron Accumulation (Nbia) - 10 Different Disorders Under Our Umbrella.
Neuroendocrine Cancer Awareness Network Inc	<a href="https://www.netcancerawareness.org/">https://www.netcancerawareness.org/</a>	Neuroendocrine, Carcinoid, Carcinoid Syndrome
Neuromuscular Disease Foundation	<a href="http://www.CureGNEM.org">www.CureGNEM.org</a>	Gne Myopathy
New Zealand Pompe Network	<a href="https://www.nzpompe.network/">https://www.nzpompe.network/</a>	Pompe Disease
Our Odyssey	<a href="https://ourodyssey.org/">https://ourodyssey.org/</a>	Disease Agnostic (All Rare Diseases)
Patient Advocate Foundation	<a href="http://www.patientadvocate.org">www.patientadvocate.org</a>	Any Chronic, Life-Threatening Or Debilitating Disease
PPP3CA	<a href="http://www.ppp3ca.org">www.ppp3ca.org</a>	Mutation On Ppp3Ca Gene
Project FAVA	<a href="https://www.projectfava.org">https://www.projectfava.org</a>	Fibro-Adipose Vascular Anomalies (Fava)
Pyruvate Kinase Deficiency Foundation	<a href="https://www.pkdf.org/">https://www.pkdf.org/</a>	Pyruvate Kinase Deficiency
Raising Hope International Friends	<a href="http://www.raisinghopeinternational.org">www.raisinghopeinternational.org</a>	Sickle Cell Disease
Rare Families Canada	n/a	Rare And Chronic Diseases (Disease Agnostic)
Recurrent Respiratory Papillomatosis Foundation	<a href="http://www.rampf.org">www.rampf.org</a>	Recurrent Respiratory Papillomatosis, Laryngeal Papillomatosis, Pulmonary Rrp, Tracheal Papillomatosis, Lung Cancer

SALUS	n/a	Rare Cancers (Desmoid, Ewings Sarcoma, Angioimmunoblastic Tcell, Others); lpf
Sappani Foundation	<a href="https://sappanifoundation.com/">https://sappanifoundation.com/</a>	Rare Diseases And Congenital Disorders Of Glycosylation (Cdg)
SATB2 Gene Foundation	<a href="http://www.satb2gene.org">www.satb2gene.org</a>	Satb2-Associated Syndrome (Aka Glass Syndrome)
SCN2A Asia Pacific	<a href="http://www.scn2aaustralia.org">www.scn2aaustralia.org</a>	Scn2A - Autism Or Epilepsy
SCN2A GEORGIAN ASSOCIATION	n/a	Scn2A Gene
Sickle Cell 101	<a href="https://www.sc101.org/">https://www.sc101.org/</a>	Sickle Cell Disease
Siegel Rare Neuroimmune Association	<a href="https://wearsrna.org/">https://wearsrna.org/</a>	Rare Neuroimmune Disorders Including: Acute Disseminated Encephalomyelitis (Adem), Acute Flaccid Myelitis (Afm), Mog Antibody Disease (Mogad), Neuromyelitis Optica Spectrum Disorder (Nmosd), Optic Neuritis (On) And Transverse Myelitis (Tm)
Sophie's Hope Foundation, Inc	<a href="http://www.sophieshopefoundation.org">www.sophieshopefoundation.org</a>	Glycogen Storage Disease Type 1B
T.E.A.M. 4 Travis (Together Ending Asplenia Mortality)	<a href="http://www.team4travis.org">www.team4travis.org</a>	Isolated Congenital Asplenia
Team Telomere	<a href="http://teamtelomere.org">http://teamtelomere.org</a>	Telomere Biology Disorders
The Akari Foundation	<a href="https://theakarifoundation.org/">https://theakarifoundation.org/</a>	Duchenne Muscular Dystrophy
The E.WE Foundation	<a href="http://www.theewefoundation.org">www.theewefoundation.org</a>	Edwards Syndrome, Trisomy 18
The Ehlers-Danlos Society	<a href="https://www.ehlers-danlos.com/">https://www.ehlers-danlos.com/</a>	Eds And Hsd
The Global Foundation for Peroxisomal Disorders	<a href="http://www.thegfpd.org">www.thegfpd.org</a>	Peroxisomal Disorders In The Zellweger Spectrum And The Related Single Enzyme Protein Deficiencies
The SHANK2 Foundation	<a href="https://shank2.org/">https://shank2.org/</a>	Shank2 Disorder
The TBCK Foundation	<a href="http://www.tbckfoundation.com">www.tbckfoundation.com</a>	Tbck Syndrome
The XLH Network, Inc.	<a href="https://www.xlhnetwork.org/">https://www.xlhnetwork.org/</a>	X-Linked Hypophosphatemia
Thrive with Pyruvate Kinase Deficiency Organization	<a href="https://thrivewithpkd.org/">https://thrivewithpkd.org/</a>	Pyruvate Kinase Deficiency
Timothy Syndrome Alliance	<a href="http://www.timothysyndrome.org">www.timothysyndrome.org</a>	Cacna1C-Related Disorders, Timothy Syndrome, Longqt8
TSC Alliance	<a href="https://www.tscalliance.org/">https://www.tscalliance.org/</a>	Tuberous Sclerosis Complex
United Mitochondrial Disease Foundation	<a href="http://www.umdf.org">www.umdf.org</a>	Mitochondrial Disorders
Uplifting Athletes Inc.	<a href="http://www.upliftingathletes.org">www.upliftingathletes.org</a>	Disease Agnostic (All Rare Diseases)
Vision for Tomorrow Foundation	<a href="https://visionfortomorrow.org">https://visionfortomorrow.org</a>	Aniridia, Albinism
wAIHA Warriors	<a href="http://waihawarriors.org">waihawarriors.org</a>	Warm Autoimmune Hemolytic Anemia
Wilhelm Foundation	<a href="http://www.wilhelmfoundation.org">www.wilhelmfoundation.org</a>	Undiagnosed Diseases
William E. Proudford Sickle Cell Fund Inc.	<a href="https://wepsicklecell.org/">https://wepsicklecell.org/</a>	Sickle Cell Disease And Trait
Zebra CARE Initiative	<a href="https://zebra-care.org/">https://zebra-care.org/</a>	Ehlers Danlos Syndrome