24 May 2025

A Historic Moment for the First-Ever WHA Resolution on Rare Diseases

On 24 May, Member States of the 78th World Health Assembly (WHA) adopted the first-ever Resolution on Rare Diseases: a remarkable milestone in the global effort to improve the lives of the over 300 million people living with a rare or undiagnosed disease. The Resolution calls on the World Health Organization Director General to develop a Global Action Plan on Rare Diseases, which represents a 10-year roadmap to strengthen health systems around the world.

Persons Living with a Rare Disease (PLWRD) face significant challenges. It takes 4-6 years on average for a rare condition to be diagnosed, even in wealthy countries. Millions of people never receive a diagnosis, even after extensive genetic testing. 95% of rare conditions have no approved treatment. The financial burden faced by persons living with rare diseases and their families as the result of high out-of-pocket medical expenses, rehabilitation and equipment costs, and lost wages is substantial, and can be catastrophic. Nearly 60% of PLWRD report facing discrimination as the result of their condition.

The adoption of the WHA Resolution is a landmark achievement demonstrating to the world that rare diseases are a global health priority and that the unique challenges and inequities faced by people living with a rare or undiagnosed disease deserve to be recognized and addressed.

Rare Diseases International (RDI) and the Coalition in Support of the Resolution would like to express their gratitude towards the Arab Republic of Egypt and Spain for their leadership in initiating the process towards this historic Resolution and for being true champions for the rare disease community. We also thank all of the other cosponsor Member States for their support in developing and adopting this Resolution.

To overcome the barriers in accessing diagnosis, treatment and care for PLWRD, the next step is to translate the Resolution into action. RDI, its members, and the over 275 members of the Coalition in Support of the Resolution stand fully prepared to support the implementation of the Resolution and advance the development of the Global Action Plan. This is urgently needed to provide national governments with a tangible framework for action with clear targets and accountability measures to reach the Global Health 2035 Goals and to make UHC a reality.

The timing of this Resolution is optimal as the Lancet Commission on Rare Diseases continues their work to develop evidence-informed recommendations to improve the rare disease ecosystem. The provisions and impact of the Resolution should inform their work, which should in turn inform the development of the Global Action Plan.

RDI urges all Member States and the WHO to now dedicate the necessary resources to implement the provisions outlined in the Resolution at national, regional and international levels, notably through appropriate consultation with the rare disease community to develop the Global Action Plan. We must ensure that this Resolution leads to real, tangible impact for the global rare disease community.

The 275 member organizations of the Coalition in support of the WHA Resolution on Rare Diseases as of May 24, 2025, are:

- 11q Latinoamerica Sindrome de Jacobsen
- A Rare Cause
- Advocacy Service for Rare and Intractable Diseases (NPO ASrid), Japan
- Abc associazione bambini cri du chat
- AFM-Téléthon
- African Rare Diseases Initiative
- Ågrenska
- ALAN Maladies Rares Luxembourg
- Ali Kimara Rare Disease Foundation
- Alianza Argentina de Pacientes (ALAPA)
- Alianza de Asociaciones de enfermedades huérfanas y poco frecuentes de Panamá (ALASER)
- Alianza de Familias afectadas por el Síndrome de Wolfram
- Alianza Iberoamericana de Enfermedades Raras (ALIBER)
- Alliance Algérienne contre les Maladies Rares
- Alianza Peruana de Enfermedades Visuales (ALPEVI)
- APAMII Miopatias Inflamatorias
- Arachnoiditis & Chronic Meningitis Collaborative ACMCRN
- ARVC-Selbsthilfe e.V.
- Asia Pacific Alliance for Rare Disease Organizations (APARDO)
- ASMD Spain
- Asociación Colombiana de Médicos Genetistas
- Asociación Colombiana de Pacientes con Enfermedades de Depósito Lisosomal y otras Enfermedades Huérfanas-Raras (ACOPEL)
- Asociación de Desórdenes del Ciclo de la Urea y Metabólicas (ADCUM)
- Asociación Enfermedad de Kawasaki
- Asociación de Enfermedades Raras de Benidorm y Comarca (AERBECO)
- Asociación de Enfermedades Raras D´Genes
- Asociación Enfermedades Raras Elche (AER-ELX)
- Asociación de Enfermedades Suprarrenales (ASOES) Panamá
- Asociación Española de afectados por Malformaciones Cráneo-cervicales (AEMC)
- Asociación Española de Enfermos por Pseudoxantoma Elástico
- Asociación Española de Familiares y Enfermos de Wilson
- Asociación Española de Familias Ataxia Telangiectasia (AEFAT)
- Asociación Española de Hiperplasia suprarrenal congénita (AEHSC)
- Asociación Española de Nevus Gigante Congénito (ASONEVUS)
- Asociación Española de Paraparesia Espástica Familiar (AEPEF)
- Asociación Española Quistes Tarlov
- Asociación de Familiares y Afectados de Lipodistrofias (AELIP)
- Asociación de Hemoglobinuria Paroxítica Nocturna

- Asociación Humanitaria de Enfermedades Degenerativas y síndromes de la Infancia y Adolescencia (AHEDYSIA)
- Asociación de Hipotensión Intracraneal y Fugas de Líquido Cefalorraquídeo (AHIFUGA)
- Asociación Madrileña de Osteogénesis Imperfecta
- Asociación Nacional de Afectados por el Síndrome del Maullido de Gato (ASIMAGA)
- Asociación Nacional Familias G.A
- Asociación Osteogénesis Imperfecta del Perú (AOI-Perú)
- Asociación Quilomicronemia Familiar
- Asociación Retina Panamá
- Asociación Sarcomas Grupo Asistencial (ASARGA)
- Associação de Apoio aos Pacientes e Familiares com Trombocitopenia Imune (PTI Brasil)
- Association ADEM des Maladies Rares
- Association Aux Pas du Coeur
- Association of Genetically Inherited Disease Patients and Peers “Saknes”
- Association Luxembourgeoise du Syndrome de Rett
- Association Shifa des Maladies NeuroMusculaires (ASMNM)
- Associazione Italiana Neuromielite Ottica (AINMO)
- ausEE Inc.
- Australian NPC Disease Foundation Inc
- Beacon for Rare Diseases
- BioTech Sphere Research, India | Unit of NeoNexus Healthcare Pvt Ltd
- BLACKSWAN Foundation
- Blood Patients Protection Council, Kerala, India
- Cambridge Rare Disease Network
- Canadian Organization for Rare Disorders (CORD)
- Canadian Rare Disease Network
- Cardiac Community Advocacy and Support Initiative
- Casa dos Raros
- Casa Hunter
- Centre-Alliance for Rare Disease in Rwanda
- Centre for Human Metabolomics, North-West University
- Chiari Argentina
- Child and Youth Care Zimbabwe
- Children's HeartLink
- China Alliance for Rare Disease (CHARD)
- Colaborativa para Enfermedades Poco Frecuentes en el Caribe y América Latina (CEPCAL)
- Colectivo Los Pacientes Importan (Perú)
- Comité Español de Representantes de Personas con Discapacidad (CERMI)Confederación Española de Personas con Discapacidad Física y Orgánica (COCEMFE)
- Comunidad de Ostomizados

- Congenital Adrenal hyperplasia Research, Education & Support Foundation, DBA: CARES Foundation, Inc.
- Conquistando Escalones Association
- Corporacion Familia Miastenia Gravis Chile
- Cure CMD
- Cutis Laxa Internationale
- Cystinosis Ireland
- Dakshayani and Amaravati Health and Education
- Debra Jordan
- DEBRA International
- Dimus Chile
- Dravet México
- Dravet Syndrome Foundation Spain (Fundación Síndrome de Dravet)
- Duchenne Muscular Dystrophy Association of Hong Kong
- EDS Lëtzebuerg a.s.b.l.
- The Egyptian Scientific Foundation of Rare Diseases in Children (ESFRD)
- Empowered By Us
- Enfermedades Raras en El Caribe y América Latina (ERCAL)
- Esperantra
- EspeRare Foundation
- European Children's Hospitals Organisation
- European Gaucher Disease (GD)/Rare Disease Network
- European Hematology Association (EHA) Gaucher's Disease (GD) Task Force
- European Huntington Association VZW
- EURORDIS - Rare Diseases Europe
- EveryLife Foundation
- FAIM - Association for Autoimmune Diseases
- FAMILIAS AME PERÚ
- Federación Argentina de Enfermedades Poco Frecuentes (FADEPOF)
- Federación de Asociaciones de Distrofias Hereditarias de Retina de España (FARPE)
- Federación Chilena de Enfermedades Raras (FECHER)
- Federación Colombiana de Enfermedades Raras (FECOER)
- Federación Costarricense de Enfermedades Raras
- Federación Ecuatoriana de enfermedades raras (FERPOF)
- Federación de Enfermedades Poco Frecuentes Chile (FENPOF CHILE)
- Federación Española de Enfermedades Raras (FEDER)
- Federación Mexicana de Enfermedades Raras (FEMEXER)
- Federación Peruana de Enfermedades Raras (FEPER)
- Federation of European Patients Groups affected by a Rare/Genetic Kidney Diseases (FEDERG)
- FH Europe Foundation
- Fibromuscular Dysplasia Society of America (FMDSA)
- The Finnish Network for Rare Diseases
- Flutters and Strutters

- FOD Family Support Group
- Fondazione Telethon
- Forset Hayah Foundation for Rare Disease
- Foundation for Neuromuscular Support Nigeria
- Fragile X International
- Fundación AHUCE
- Fundación AME Costa Rica
- Fundación Ayúdanos a Respirar
- Fundación Charcot Chile
- Fundación Colombiana Para Enfermedades Huérfanas (FUNCOLEHF)
- Fundación Colombiana Para Fibrosis Quística (FIQUIRES)
- Fundación Ecuatoriana para Distrofia Muscular y Enfermedades Raras (FEDIMURA)
- Fundación de Hemisferectomia
- Fundación Menkes Chile
- Fundación del Síndrome de Vogt Koyanagi Harada y Uveítis Chile
- Fundación Síndrome Wolf Hirschhorn (FSWH 4p-)
- Fundación Sonrie SURF1
- Fundación Taiyari compartir por la inclusión AC
- Fundación Uruguaya para la Investigación de las Enfermedades Raras (FUPIER)
- GABA-A Alliance
- GBS-CIDP Foundation International
- Genetic Alliance
- Genetic Alliance Australia
- Genetic Support Network of Victoria
- Geniin
- Georgian Alliance for Rare Diseases
- Georgian Foundation for Genetic and Rare Diseases (GeRaD)
- Gillette Children's Specialty Healthcare
- Global Albinism Alliance
- Global ARCH
- Global Nursing Network for Rare Diseases
- GlobalSkin (International Alliance of Dermatology Patient Organizations)
- Gluten Intolerance Group of North America
- Glut1 Belgium ASBL
- Haiti Cholera Research Funding Foundation Inc USA (HCRFF)
- HHT Sverige Patient Association
- Hirschsprung Argentina
- Hispanic Society for Rare Diseases
- Hope for Stomach Cancer
- Hospital Sant Joan de Déu-Barcelona (SJD Barcelona Children's Hospital)
- Huntington’s Disease Youth Organization
- The Inclusion Gateway Ltd
- Indian Organization for Rare Diseases
- Indian Patients Society for Primary Immunodeficiency (IPSPI)

- Indonesian Spinal Muscular Atrophy Community
- IndoUSrare
- Iniciativa Pensemos en Cebras México
- Instituto Promoviendo Desarrollo Social IPRODES
- Instituto Unidos pela Vida
- Instituto Vidas Raras
- Interessengemeinschaft Hämophiler e.V (IGH)
- International Agency for the Prevention of Blindness (IAPB)
- International Alliance of Patient Organizations (IAPO)
- International Bureau for Epilepsy
- International Federation for Spina Bifida and Hydrocephalus
- International Federation Psoriasis Association (IFPA)
- International FOXP1 Foundation
- International Gaucher Alliance (IGA)
- International MPS Network
- International Patient Organisation for Primary Immunodeficiencies (IPOPI)
- International Pemphigus and Pemphigoid Foundation
- International Prader-Willi Syndrome Organisation (IPWSO)
- International Rare Disease Research Consortium (IRDiRC)
- International Society of Paediatric Oncology (SIOP)
- Jaz Mitocondriales Argentina
- Jordan Society of Pathology
- Khmelnytskyi City Children's Hospital and Rare Disease Center
- kosek - National Coordination Rare Diseases Switzerland
- Krishnan Family Foundation
- Kyrgyz Hemophilia Society
- Latin Americas Patients Academy
- Latvian Alliance of Rare Diseases
- Llapan kallpa - Organización de Pacientes con Hipertensión Pulmonar Perú
- LMNA Cardiac
- Malaysian Rare Disorders Society
- MarylandRARE
- MBM Future Health
- Medics for Rare Disease
- Medscape Education Global
- MENA Organization for Rare Diseases
- MLD Foundation
- MSUD Family Support Group
- Muscular Dystrophy Pakistan
- National Alliance for Rare Diseases Support Malta
- National Fabry Disease Foundation
- National Organisation for Rare Diseases of Serbia (NORBS)
- National Rare Diseases Registry System of China (NRDRS)
- NCBRS Worldwide Foundation

- NCD Alliance Kenya
- Niemann-Pick B-RS
- NiemannPick India
- No Stomach For Cancer
- Objetivo Diagnostico, Asociación Nacional de Personas Sin Diagnóstico
- OJQ KONSUMATORI / NGO THE CONSUMER
- Organización Mexicana de Enfermedades Raras
- Organization for Rare Diseases India (ORDI)
- Orphanet
- Osteogenesis Imperfecta Federation Europe (OIFE)
- Partnership for Quality Medical Donations
- Patient Academy for Innovation and Research
- Patient and CommunityWelfare Foundation of Malawi (PAWEM)
- Pathways for Rare and Orphan Solutions
- Plataforma de Organizaciones de Pacientes
- Psoriasis Asia Pacific
- Psoriasis Philippines
- ProRaris - Swiss Alliance of Rare Disease Patient Organizations
- Pulmonary Hypertension Society (Latvia)
- Raramente, CRL
- Rare Care Centre, Western Australia
- Rare Disease Ghana Initiative (RDGI)
- Rare Disease Hong Kong
- Rare Disease Iraq
- Rare Disease Male Mental Health Support Group
- Rare Diseases Center, HUS Helsinki University Hospital, Finland
- Rare Diseases Lesotho Association (RDLA)
- Rare Diseases International (RDI)
- Rare Diseases Portugal
- Rare Diseases South Africa NPC
- Rare Diseases Uganda
- Rare Disorders Kenya
- Rare Disorders New Zealand
- Rare Disorders Zimbabwe (formerly Child and Youth Care)
- Rare Patient Voice
- Rare Voices Australia
- RD-Portugal, União das Associações das Doenças Raras de Portugal
- Red de Enfermedades Raras de Costa Rica
- Red Mexicana de Enfermedades Raras (ReMexER)
- Relapsing Polychondritis Awareness & Support
- Remember The Girls
- Retina International
- Romanian National Alliance for Rare Diseases
- SAF ESPAÑA

- Save Sight Now Europe
- Senegalese Society of Human Genetics S2GH
- Sickle Cell Advocates of Rochester
- Skraban-Deardorff Syndrome Foundation (SKDEAS)
- Sociedad Española de Medicina de Familia y Comunitaria (semFYC)
- Sociedad Latina de Hipertensión Pulmonar
- Sociedad Mexicana para Porfiria
- Speaking on Cancer Patient Advocacy
- Thai Rare Disease Foundation
- Thalassemia Foundation Ghana
- The Children's Hyperinsulinism Charity UK and Ireland
- The Ehlers-Danlos Society
- The Oxalosis and Hyperoxaluria Foundation
- Trastorno Arnold Chiari Panamá
- Unique (Rare Chromosome Disorder Support Group)
- Vietnamese Organization for Rare Diseases
- Vivir con Chiari
- Voice of Rare Diseases Indonesia
- Wilhelm Foundation
- Wiskott-Aldrich Foundation
- Women Safety and Justice Initiatives (WSJI)
- World Alliance of Pituitary Organizations
- World Federation of Hemophilia (WFH)
- XLH Chile
- Zambia Heart and Stroke Foundation

Individual endorsements:

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