Call to Action for Member States to Adopt the World Health Assembly Resolution on Rare Diseases at WHA78

We stand at a pivotal moment in global health, where the collective action of Member States has the potential to transform the lives of the over 300 million persons living with a rare disease (PLWRD) and many more persons living with an undiagnosed disease (PLWUD) as well as their families and caregivers. The Arab Republic of Egypt and Spain have put forward a historic World Health Assembly (WHA) Resolution, co-sponsored by 24 other Member States, which calls for a comprehensive approach to rare diseases, ensuring equitable access to diagnosis, treatment, and care. The Resolution, "**Rare diseases: a global health priority for equity and inclusion**," which calls on the Director General of the World Health Organization (WHO) to develop a Global Action Plan on Rare Diseases (GAPRD), represents an opportunity to make a meaningful difference in the lives of those living with these conditions, to leave no one behind.

The Coalition for the Resolution on Rare Diseases, which represents 245 organizations including patient associations, research centers, and healthcare institutions (list in annex), urges all Member States to adopt this Resolution and to dedicate the necessary resources to implement its provisions at national, regional and international levels. Rare diseases, though individually rare, collectively impact hundreds of millions of people across the globe. These individuals face significant barriers to healthcare access, including delayed diagnosis, limited treatment options, lack of specialized care and support, stigma, mental health burden, economic impact and social exclusion. This Resolution has the potential to elevate the visibility of both rare and undiagnosed diseases within the global health ecosystem, creating pathways for earlier and more accurate diagnoses, improved care models, and expanded treatment, care and support options. **By adopting and implementing this Resolution, we can work towards a future where PLWRD and PLWUD are included in Universal Health Coverage (UHC) efforts and ultimately receive the care, support, and recognition they deserve.**

It is time to prioritize rare diseases on the global health agenda. We call on the WHA to:

1. **Adopt the WHA Resolution on Rare Diseases**: Formalize commitment at the national level to the WHA's call for a global action plan to address rare diseases.
2. **Commit Resources**: Allocate the necessary attention, funding, infrastructure, and research support to improve care and treatment options for rare diseases, and develop the GAPRD.

We call on WHO to:

1. **Establish a consultation process:** Elaborate a comprehensive engagement plan in close collaboration with Non-State Actor organizations representing PLWRD and any other relevant stakeholders, including PLWRD and PLWUD, communities, and civil society.
2. **Dedicate Resources:** Ensure sufficient sustainable resources required to develop the GAPRD.

3. **Support Member States:** Provide the necessary technical support, policy guidance, and capacity-building assistance to Member States to implement the Resolution.

We call on governments, policy-makers, healthcare providers, and other stakeholders to:

1. **Support the development of the GAPRD**: Engage and cooperate with the WHO in the development of the GAPRD, participate in consultations, and dedicate the necessary resources and expertise to make it a success.
2. **Collaborate Globally**: Partner with other nations, international organizations, patient advocacy groups, health care providers, research centers, and the private sector to share knowledge, research, and best practices in rare disease care.
3. **Ensure Equity**: Guarantee that PLWRD and PLWUD have access to timely diagnosis, care, treatments, support services, and clinical trials - regardless of their location, culture, gender or socio-economic status.

This is a call for solidarity, action, and commitment to those who need our help the most. Together, we can make this vision a reality, ensuring a healthier, more inclusive future for all in the pursuit of UHC.

Let us take this step, for every PLWRD and PLWUD around the world. It is time to make rare diseases a global health priority and **adopt the WHA Resolution on Rare Diseases calling for a Global Action Plan.**

Annex: Coalition Membership

The 245 member organizations of the Coalition in support of the WHA Resolution on Rare Diseases as of April 3, 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
- Asociacion 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)
- 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)
- 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 International
- Dimus Chile
- 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)
- EspeRare Foundation
- European Children's Hospitals Organisation
- European Gaucher Disease (GD)/Rare Disease Network
- 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)
- 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 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
- 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)
- Hirschsprung Argentina
- Hope for Stomach Cancer
- Hospital Sant Joan de Déu-Barcelona (SJD Barcelona Children's Hospital)
- Huntington’s Disease Youth Organization
- Indian Organization for Rare Diseases
- Indian Patients Society for Primary Immunodeficiency (IPSPI)
- Indonesian Spinal Muscular Atrophy Community
- 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 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)
- Jaz Mitocondriales Argentina
- Jordan Society of Pathology
- Krishnan Family Foundation
- Kyrgyz Hemophilia Society
- Latvian Alliance of Rare Diseases
- 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, Asociacion Nacional de Personas Sin Diagnostico
- 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 Lesotho Association (RDLA)
- Rare Diseases International (RDI)
- Rare Diseases Portugal
- Rare Diseases South Africa NPC
- Rare Diseases Uganda
- Rare Disorders Kenya
- 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)
- Remember The Girls
- Retina International
- Romanian National Alliance for Rare Diseases
- SAF ESPAÑA
- Sickle Cell Advocates of Rochester
- Skraban-Deardorff Syndrome Foundation (SKDEAS)
- Sociedad Latina de Hipertensión Pulmonar
- Sociedad Mexicana para Porfiria
- Speaking on Cancer Patient Advocacy
- Thalassemia Foundation Ghana
- The Children's Hyperinsulinism Charity UK and Ireland
- The Ehlers-Danlos Society
- The Oxalosis and Hyperoxaluria Foundation
- Transtorno Arnold Chiari Panamá
- 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
- XLH Chile
- Zambia Heart and Stroke Foundation

Individual endorsements:

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