RARE DISEASES INTERNATIONAL

23 January 2025

Dr. Tedros Adhanom Ghebreyesus
Director-General
World Health Organization (WHO)
Avenue Appia 20
1211 Geneva, Switzerland

Subject: Open Letter from the Coalition in support of the WHA Resolution on Rare Diseases

Dear Dr. Tedros,

On behalf of the **Coalition in support of the WHA Resolution on Rare Diseases**, which unites global stakeholders advocating for the 300 million persons living with a rare disease (PLWRD), we are writing to express our strong support for the draft resolution, "**Rare Diseases: A Global Health Priority for Equity and Inclusion**", led by the Arab Republic of Egypt and Spain, and co-sponsored by Brazil, Chile, France, Kuwait, Luxembourg, Malaysia, Palestine, Panama, the Philippines, and Qatar.

This draft resolution, which is set to be discussed at the WHO Executive Board in February, represents a vital opportunity to prioritize rare diseases on the global health agenda.

We are aware of the recent developments regarding relations between the United States and the WHO and the funding implications, but we call upon the leadership of Member States and the WHO to find a solution and continue to progress the WHA Resolution on Rare Diseases and Global Action Plan. The Coalition emphasizes the importance of this Resolution in advancing equity and inclusivity, aligning closely with the principles of Universal Health Coverage (UHC). As recognized in the UN Political Declarations on UHC in 2019 and 2023, **UHC cannot be truly achieved if the specific challenges of PLWRD are not addressed**, as millions continue to face delayed diagnosis and misdiagnosis, inadequate treatment options, financial burdens, stigma, and exclusion from health and social systems.

While the draft Resolution is a critical step forward, its success hinges on WHO's leadership in supporting its adoption and, if adopted, its implementation. To facilitate the adoption of the Resolution and to ensure, once adopted, that the Resolution leads to meaningful outcomes for PLWRD and their families, we urge WHO to:

1. **Dedicate Resources to Develop a Global Action Plan on Rare Diseases**: As requested by the 12 co-sponsor Member States in the draft Resolution, WHO must dedicate the required resources within the WHO budget to enable the development of a comprehensive Global Action Plan (GAP);
2. **Support Member States in Adopting the Resolution at the WHA**: WHO's leadership is crucial in fostering collaboration, providing technical expertise, and building consensus among Member States to secure the Resolution's adoption at the WHA in May 2025.
3. **Facilitate Implementation of the Resolution and the GAP**: WHO must work closely with Member States to ensure the Resolution's objectives are integrated into national

health strategies and systems, particularly within UHC frameworks, to guarantee equitable access to care for PLWRD.

4. **Engage PLWRD and Their Advocates**: The voices of PLWRD, their families, and the organizations representing them must be central to the GAP's development and implementation, ensuring that their lived experiences guide solutions.
5. **Promote International Collaboration**: Address the shared challenges of rare diseases by fostering global partnerships for research, data sharing, capacity building, and innovation.

The **Coalition for the WHA Resolution on Rare Diseases** is fully committed to supporting WHO and Member States in advancing this agenda. We bring together a diverse network of experts, advocates, and resources to assist in developing the GAP and ensuring the Resolution leads to measurable improvements for PLWRD and their families worldwide.

We respectfully request a meeting with WHO representatives to explore how the Coalition can further support these efforts. Together, we can ensure that the Resolution is adopted and implemented effectively, and that it drives progress towards UHC that includes *everyone*, including those living with rare diseases.

Thank you for your unwavering leadership and dedication to global health equity.

Yours sincerely,

Alexandra Heumber Perry
Chief Executive Officer, Rare Diseases International
On behalf of the Coalition in support of the WHA Resolution on Rare Diseases

cc: [Ruediger Krech, Ulrike Schwerdtfeger]

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Coalition in support of the WHA Resolution on Rare Diseases

The 131 member organizations of the Coalition in support of the WHA Resolution on Rare Diseases as of January 23, 2025, are:

- 11q Latinoamerica Sindrome de Jacobsen
- A Rare Cause
- Advocacy Service for Rare and Intractable Diseases (NPO ASrid), Japan
- AFM-Téléthon
- Ågrenska
- ALAN Maladies Rares Luxembourg
- Ali Kimara Rare Disease Foundation
- Alianza de Asociaciones de enfermedades huérfanas y poco frecuentes de Panamá (ALASER)
- Alianza Iberoamericana de Enfermedades Raras (ALIBER)
- Alliance Algérienne contre les Maladies Rares
- Alianza Peruana de Enfermedades Visuales (ALPEVI)
- APAMII Miopatias Inflamatorias

- ASMD Spain
- Asociación de Enfermedades Suprarrenales (ASOES) Panamá
- Asociación Española de Familiares y Enfermos de Wilson
- Asociación Retina Panamá
- Associação de Apoio aos Pacientes e Familiares com Trombocitopenia Imune (PTI Brasil)
- Association Aux Pas du Coeur
- Association Luxembourgeoise du Syndrome de Rett
- Canadian Organization for Rare Disorders (CORD)
- Canadian Rare Disease Network
- Casa dos Raros
- Casa Hunter
- Centre-Alliance for Rare Disease in Rwanda
- Child and Youth Care Zimbabwe
- China Alliance for Rare Disease (CHARD)
- Colaborativa para Enfermedades Poco Frecuentes en el Caribe y América Latina (CEPCAL)
- Colectivo Los Pacientes Importan (Perú)
- Corporacion Familia Miastenia Gravis Chile
- Cutis Laxa Internationale
- Cystinosis Ireland
- Dakshayani and Amaravati Health and Education
- Debra International
- Dimus Chile
- EDS Lëtzebuerg a.s.b.l.
- Enfermedades Raras en El Caribe y América Latina (ERCAL)
- EspeRare Foundation
- European Gaucher Disease (GD)/Rare Disease Network
- EURORDIS - Rare Diseases Europe
- EveryLife Foundation
- FAMILIAS AME PERÚ
- Federación Argentina de Enfermedades Poco Frecuentes (FADEPOF)
- Federación Chilena de Enfermedades Raras (FECHER)
- Federación Colombiana de Enfermedades Raras (FECOER)
- Federación Ecuatoriana de enfermedades raras (FERPOF)
- 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
- Flutters and Strutters
- FOD Family Support Group
- Forset Hayah Foundation for Rare Disease
- Fragile X International
- Fundación del Síndrome de Vogt Koyanagi Harada y Uveítis Chile
- Fundación Ecuatoriana para Distrofia Muscular y Enfermedades Raras (FEDIMURA)
- Fundación Menkes Chile
- 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
- Gluten Intolerance Group of North America
- Haiti Cholera Research Funding Foundation Inc USA (HCRFF)
- 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)
- Interessengemeinschaft Hämophiler e.V (IGH)
- International Alliance of Patient Organizations (IAPO)
- International Federation Psoriasis Association (IFPA)
- 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)
- Instituto Promoviendo Desarrollo Social IPRODES
- Instituto Unidos pela Vida
- Instituto Vidas Raras
- Jordan Society of Pathology
- Krishnan Family Foundation
- Kyrgyz Hemophilia Society
- LMNA Cardiac
- Malaysian Rare Disorders Society
- MENA Organization for Rare Diseases
- MLD Foundation
- National Organisation for Rare Diseases of Serbia (NORBS)
- NCD Alliance Kenya
- No Stomach For Cancer
- 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
- Rare Care Centre, Western Australia

- Rare Disease Ghana Initiative (RDGI)
- Rare Disease Hong Kong
- Rare Disease Male Mental Health Support Group
- Rare Diseases Lesotho Association (RDLA)
- Rare Diseases International (RDI)
- Rare Diseases South Africa NPC
- Rare Diseases Uganda
- Rare Disorders Kenya
- Rare Voices Australia
- Red de Enfermedades Raras de Costa Rica
- Remember The Girls
- Sickle Cell Advocates of Rochester
- Skraban-Deardorff Syndrome Foundation (SKDEAS)
- Sociedad Latina de Hipertensión Pulmonar
- 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
- Voice of Rare Diseases Indonesia
- Wiskott-Aldrich Foundation
- Women Safety and Justice Initiatives (WSJI)
- XLH Chile