Coalition in Support of the WHA Resolution on Rare Diseases
Statement - 17 January 2025

The Coalition, composed of people with lived experience, and rare disease champions, advocates, and allies, supports the actions towards a World Health Assembly (WHA) Resolution on Rare Diseases, which will enhance visibility, equity, and agency for persons living with a rare disease (PLWRD) by addressing global disparities in access to diagnosis, care, support, treatment, and research.

Despite significant recent advances in health innovation, research and development, and progress towards Universal Health Coverage (UHC), rare diseases remain a significant unmet need in healthcare. As a result of limited health budgets, resources, and expertise, PLWRD across the globe continue to face unique challenges and widespread inequity in accessing appropriate care and support.

We applaud the progress made thus far by Member States towards improving the lives of the more than 300 million PLWRD worldwide and urge governments to strengthen collaboration towards a better global ecosystem for rare diseases and ensure greater equity for all PLWRD.

The Coalition strongly supports the WHA Resolution on Rare Diseases and its call for the World Health Organization to develop a Global Action Plan on Rare Diseases. A Global Action Plan on Rare Diseases is urgently needed to create a pivotal platform for collective action, through a collaborative and multisectoral approach, and cement rare diseases as a priority on the global health agenda. It will provide 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.

We urge Member States to support and adopt the WHA Resolution calling for a Global Action Plan on Rare Diseases, and take tangible steps in ensuring more equitable access to recognition, patient-centered diagnosis, care, support, research, and development of therapies for PLWRD, to truly leave no one behind in the pursuit of UHC and the 2030 United Nations Sustainable Development Goals.

We urge all civil society organizations supportive of the WHA Resolution on Rare Diseases to join the Coalition in support of the WHA Resolution on Rare Diseases and endorse the above statement by completing this short form.

Coalition in support of the WHA Resolution on Rare Diseases

The member organizations of the Coalition in support of the WHA Resolution on Rare Diseases as of January 17, 2025, are:

Advocacy Service for Rare and Intractable Diseases (NPO ASrid), AFM-Téléthon, Ågrenska, Asociación de Enfermedades Suprarrenales (ASOES) Panamá, Associação de Apoio aos Pacientes e Familiares com Trombocitopenia Imune (PTI Brasil), Association Aux Pas du Coeur, Canadian Organization for Rare Disorders (CORD), Canadian Rare Disease Network, Casa Hunter, Centre-Alliance for Rare Disease in Rwanda, Child and Youth Care Zimbabwe, Cutis Laxa Internationale, Dakshayani and Amaravati Health and Education, Dimus Chile, The Ehlers-Danlos Society, EspeRare

Foundation, EURORDIS - Rare Diseases Europe, Federación Argentina de Enfermedades Poco Frecuentes (FADEPOF), Federación Española de Enfermedades Raras (FEDER), Federation of European Patients Groups affected by a Rare/Genetic Kidney Diseases (FEDERG), FH Europe Foundation, Fragile X International, Fundación Menkes Chile, Genetic Alliance, Genetic Support Network of Victoria, Georgian Foundation for Genetic and Rare Diseases (GeRaD), Global Albinism Alliance, Global Nursing Network for Rare Diseases, Indian Organization for Rare Diseases, Interessengemeinschaft Hämophiler e.V (IGH), International Alliance of Patient Organizations (IAPO), International Federation Psoriasis Association (IFPA), International Patient Organisation for Primary Immunodeficiencies (IPOPI), International Prader-Willi Syndrome Organisation (IPWSO), International Rare Disease Research Consortium (IRDiRC), Krishnan Family Foundation, Malaysian Rare Disorders Society, MENA Organization for Rare Diseases, Orphanet, Patient Academy for Innovation and Research, Rare Care Centre, Rare Disease Ghana Initiative, Rare Diseases Lesotho Association (RDLA), Rare Diseases International (RDI), Rare Voices Australia, Red de Enfermedades Raras de Costa Rica, and Skraban-Deardorff Syndrome Foundation (SKDEAS).