



RARE
DISEASES
INTERNATIONAL



NGO COMMITTEE FOR
RARE DISEASES

STATEMENT

Rare Diseases International and its partners call on United Nations Member States to make Universal Health Coverage a reality for People Living with Rare Diseases

21 September 2023, New York – Today, at a high-level meeting at the United Nations Headquarters, UN Member States gathered to accelerate progress towards achieving Universal Health Coverage (UHC) by 2030. In conjunction with this momentous occasion, Rare Diseases International (RDI), EURORDIS – Rare Diseases Europe, Ågrenska and Federación Española de Enfermedades Raras (FEDER) held a formal side-event to emphasize the vital importance of including the rare disease community in UHC. The event, entitled “A Blueprint for Leaving No One Behind,” was co-organized by the Permanent Missions of Spain and Sweden to the UN and the Ministry of Public Health of the State of Qatar to underline the message that UHC cannot be truly universal unless it meets the needs of the 300 million people worldwide living with a rare disease.

The event was formally opened by Her Majesty the Queen Letizia of Spain and Her Majesty the Queen Silvia of Sweden, followed by addresses from the Ministers of Health of Spain, Sweden, Qatar, France, Malaysia, as well as representatives from the Ministries of Health of Canada and Brazil, the Ministry of Foreign Affairs of the United Arab Emirates, and the European Commission, emphasizing the need for global action on supporting PLWRD through sharing expertise, investing in scientific research, and relieving the economic burden of rare diseases.

The World Health Organization, the World Bank, the Office of the UN High Commissioner for Human Rights (OHCHR), the NGO Committee for Rare Diseases, Ågrenska, and the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO) highlighted the need for supporting the rare disease community as part of their objectives of supporting global human rights and sustainability.

The high-level, global participation in this event reflects the political momentum for rare diseases that has been growing since the 2019 Political Declaration on UHC, which marked the first time that rare diseases were included in a UN declaration adopted by all 193 Member States. This was followed by the first-ever UN resolution on rare diseases in 2021. Today’s meetings provide further evidence that the UN Member States are collectively committed to supporting the rare disease community with the objective of meeting their complex needs.

As expressed by Durhane Wong-Rieger, Chair of RDI and President of the Canadian Organization for Rare Disorders, *“Patients and families living with rare diseases across the globe are heartened by the continued commitment expressed by the global organizations as well as the national governments.”*

However, this commitment alone is not sufficient. This global commitment must now be translated into immediate action at the regional and national levels. For the more than 300 million Persons Living with a Rare Disease (PLWRD) worldwide, the time to act on the Political Declaration on Universal Health Coverage is now.

The medical, social and financial challenges faced by PLWRD were underlined during a panel of patient advocates from four different continents, moderated by Wong-Rieger. During the panel, patient advocates spoke of issues such as delays in diagnosis, limited access to services, and the high cost of treatments. The patient advocates emphasized that the financial burden of rare diseases is not limited to medical expenses: PLWRD and their families bear significant costs associated with their complex needs, including transportation and rehabilitation. Coupled with the lost income of family members serving as caregivers, who are disproportionately women, this creates a long-term financial burden, leading to the impoverishment of the rare disease population. For society, the cost of not diagnosing and not treating rare diseases exceeds the cost of timely appropriate services.

To address these challenges effectively, governments must respect the fundamental human right to health of PLWRD and recognize that their needs are linked specifically to the rarity of their condition. While each rare disease only affects a small number of people, together there are over 6000 rare diseases affecting 4% of the population of every country in the world. Without addressing the challenges of this vulnerable population, Universal Health Coverage cannot succeed.

Wong-Rieger added, *“As importantly, the assembly heard from the representatives of patient organizations working at local and national levels, how they have been able to leverage the UN UHC Declaration and the UN Rare Disease Resolution to effect meaningful advances in diagnosis, care and treatment, in collaboration with healthcare providers and other partners.”*

That is why RDI and its partners are calling on member states to mobilize efforts to provide a global framework for action, through the adoption of a World Health Assembly Resolution on Rare Diseases. Now is the time to capitalize on the political will of this moment to improve the lives of People Living with a Rare Disease through adequate funding and resources to ensure that Universal Health Coverage truly leaves no one behind.

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About Rare Diseases International

Rare Diseases International (RDI) is the global alliance of people living with a rare disease of all nationalities across all rare diseases. RDI's mission is to be a strong common voice on behalf of rare disease patients around the world, to advocate for rare diseases as an international public health priority and to represent its members and enhance their capacities. RDI has more than 85 member organisations from over 45 countries, that in turn represent rare disease patient groups in more than 150 countries worldwide.

About EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 1000 rare disease patient organisations from 74 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services

About Ågrenska

Ågrenska is a Swedish national center of competence for rare diseases and other disabilities. It is an idea-driven non-profit organization that operates on a non-profit basis. Ågrenska serves children, adolescents and their families, as well as adults with disabilities, get through activities based on a holistic approach for the purpose of optimizing the lives of people with rare diseases and other disabilities. Ågrenska operates at a local, regional, national, and international level and has had Special Consultative status within the ECOSOC since 2005.

About FEDER

The Federación Española de Enfermedades Raras (FEDER) was created in 1999 with the aim of being the hope of more than three million people living with rare diseases in Spain. Currently, FEDER is made up of 402 entities that represent a total of 1,281 rare diseases.

About the NGO Committee for Rare Diseases

The NGO Committee for Rare Diseases, created in 2015 by Ågrenska and EURORDIS-Rare Diseases Europe, is a Substantive Committee of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO). The NGO Committee is a multi-stakeholder, inclusive, global ecosystem, which works towards making rare diseases a global health priority on the UN's agenda and within public health, research, medical and social care policies and structures around the world.