



RARE
DISEASES
INTERNATIONAL



NGO COMMITTEE FOR
RARE DISEASES

Press release

The global rare disease community calls on United Nations Member States to turn Universal Health Coverage into a reality for people living with rare diseases

21 September 2023, New York – Today, at the United Nations Headquarters, Rare Diseases International (RDI) in partnership with EURORDIS-Rare Diseases Europe, Ågrenska, and FEDER, convened a historic event titled "Engaging the UN System and Member States to Achieve UHC for PLWRD: A Blueprint for Leaving No One Behind." Co-sponsored by the Permanent Missions of Spain and Sweden to the UN and supported by the Ministry of Public Health of the State of Qatar, this event delivered a resounding message: Universal Health Coverage (UHC) must encompass the unique needs of the 300 million people worldwide living with rare diseases, including the 30 million individuals in Europe.

The gathering opened with video statements from Her Majesty Queen Letizia of Spain and Her Majesty Queen Silvia of Sweden. The gathering also featured other high-profile speakers, including France's Health Minister, Aurélien Rousseau, Sweden's Health Minister, Acko Ankarberg Johansson, and Spain's Health Minister, José Manuel Miñones Conde. Further contributions came from Health Ministers Dr. Hanan Mohammed Al-Kuwari of Qatar and Dr. Zaliha Mustafa of 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 European Commission Director-General Sandra Gallina. The speakers delivered impassioned addresses, emphasizing the necessity for global collaboration to support people living with rare diseases (PLWRD). They also stressed the importance of sharing expertise, investing in scientific research, and relieving the economic burdens faced by rare disease-affected individuals and their families.

EURORDIS-Rare Diseases Europe interprets the strong political commitment of the European Commission and its Member States at this event as a profound dedication by the European Union to achieve Universal Health Coverage for its citizens living with rare diseases. This commitment translates to improved access to essential services, including earlier and better diagnosis, integrated medical and social care, appropriate treatments when available, and reduced out-of-pocket expenses for affected families.

In the words of Yann Le Cam, Chief Executive of EURORDIS-Rare Diseases Europe:

"The commitment of the EU and its Member States to Universal Health Coverage at the United Nations General Assembly and its support for the inclusion of rare diseases goes far beyond the European Union. It signals that the EU is ready to partner with WHO Europe to support rare diseases policy and actions globally, through WHO and all its Member States."

On a global scale, the World Health Organization (WHO), alongside other United Nations Agencies including the World Bank and the Office of the UN High Commissioner for Human Rights (OHCHR), as well as the NGO Committee for Rare Diseases and the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO), have all highlighted the need for supporting the rare disease community as part of their objectives of supporting global human rights and sustainability.

However, commitment alone is not sufficient. To address the unique challenges of people with rare diseases and their families – including issues like delayed diagnosis, limited access to essential services, and the high costs associated with treatments – European and national policymakers must prioritise and respect the fundamental human right to health for people living with a rare disease.

It's essential to recognise that their needs are intricately linked to the rarity of their conditions. While each rare disease affects a relatively small number of people, when taken together, there are over 6000 rare diseases impacting approximately 4% of the population in every country around the world.

This global commitment must now be translated into immediate action at regional, European, and national levels. For the more than 300 million people living with a rare disease (PLWRD) worldwide and the 30 million in Europe, the time to act is now. Failing to address the challenges faced by this vulnerable population undermines the success of Universal Health Coverage.

That is why Rare Diseases International, EURORDIS-Rare Diseases Europe and its partners are calling on Member States to mobilise efforts to provide a global framework for action, through the adoption of a World Health Assembly Resolution on Rare Diseases.

Additionally, in Le Cam's perspective, *"achieving Universal Health Coverage for individuals with rare diseases and ensuring that no one is left behind in Europe can be achieved through the implementation of a European Action Plan for Rare Diseases."* This initiative has garnered support from 22 EU Member States and is a priority during the current Spanish EU Presidency.

Therefore, EURORDIS is also calling on European policymakers to move forward with a European action plan on rare diseases, which has been long awaited by the 30-million rare disease community.

Now is the time to capitalise 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 EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 930 rare disease patient organisations from 73 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 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 60 member organisations from over 30 countries, that in turn represent rare disease patient groups in more than 100 countries worldwide.

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.

About rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date affecting an estimated 30 million people in Europe and 300 million worldwide. 72% of rare diseases are genetic whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative. 70% of those genetic rare diseases start in childhood.

Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offerings inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.