



Statement

UN Member States include rare diseases in political declaration on universal health coverage

23 September 2019, New York – Today at a high-level meeting at the United Nations (UN) headquarters, UN Member States adopted a [political declaration](#) on universal health coverage (UHC) that includes mention of rare diseases. This marks a hugely significant milestone for the rare disease community, with rare diseases being included for the first time within a UN declaration adopted by all 193 Member States.

In attendance at today's meeting and representing the rare disease community were **Yann Le Cam**, Chief Executive Officer of EURORDIS-Rare Diseases Europe, member of the Council of Rare Diseases International (RDI) and member of the Executive Committee of the NGO Committee for Rare Diseases, and **Durhane Wong-Rieger**, Chair of the Council of RDI, President of the Canadian Organization for Rare Disorders and Member of the Board of the NGO Committee for Rare Diseases.

Contributing to the proceedings, EURORDIS-Rare Diseases Europe, RDI and the NGO Committee for Rare Diseases submitted a joint [written statement](#) outlining the case for including the **300 million people worldwide living with a rare disease** within universal health coverage to ensure that this population is not left behind.

Also in attendance at today's meeting were a number of key figures in international health policy, including Dr Tedros, Director-General of the World Health Organization (WHO), Ms Michelle Bachelet, UN High Commissioner for Human Rights and Mr Keizo Takemi, WHO UHC Goodwill Ambassador.

Double milestone for the rare disease community

Durhane Wong-Rieger said, "The inclusion of people living with a rare disease within the declaration is the result of years of coordinated advocacy work from a number of organisations and led by Rare Diseases International, EURORDIS and the NGO Committee for Rare Diseases. The rare disease community remains committed to driving support for universal health coverage, to collaborating with relevant actors, to holding governments to account and to ensuring that traditionally left-behind communities like ours are actively engaged to plan, budget and implement the policies that will ensure services are more acceptable, appropriate and sustainable".

Yann Le Cam commented, "This is the most important health-related text in the 15 years of the 2030 Agenda for Sustainable Development. It reinforces and creates a dynamic in almost all countries in the world to increase the percentage of the population (including people with rare diseases) benefitting from health coverage, to enlarge the list of care services covered, and to increase the percentage of healthcare expenses covered by public resources. The declaration gives us the most robust grounds to date to move towards a UN resolution on rare diseases".

Anders Olauson, Chair of the NGO Committee and Chairman of the Ågrenska National Centre for Rare Diseases (Sweden), said, "This declaration represents a double milestone for the rare disease community. At a political level, the inclusion of rare diseases alongside communicable and non-communicable diseases, impairments and disabilities, means people living with rare diseases are no longer invisible to the international health policy agenda. At a practical level, the text also provides leverage for local stakeholders to call for national action to provide health services for people affected by a rare disease".

Advocacy steps to now

EURORDIS, RDI and the NGO Committee for Rare Diseases have worked together over the last three years to advocate for people living with rare diseases to be included within universal health coverage. Recent advocacy actions include:

- Numerous meetings with Permanent Missions of Member States to the UN and UN officials in Geneva and New York.
- Meetings with the Office of the UN Special Rapporteur on the rights of persons with disabilities, the UN Special Rapporteur on the Right to Health, and Dr Tedros, Director-General of the WHO to discuss the [inclusion of rare diseases within UHC and SDG 3 on health](#).
- Submission of an official written statement – [The Human Rights of People living with a Rare Disease](#) - presented at the Human Rights Council 38th Session in June 2018.
- On **21 February of this year**, a Rare Disease Day Policy Event was held at the UN's New York Headquarters, at which EURORDIS, RDI and the NGO Committee for Rare Diseases [called for](#) the integration of rare diseases into the UN political declaration on UHC.
- **May 2019** saw rare diseases being featured for the first time on the agenda of the World Health Assembly through events hosted and contributed towards by RDI. Developed in consultation with its members, the RDI position paper, [Rare Diseases: Leaving no one behind in Universal Health Coverage](#), has been shared and referenced at a number of meetings and has been key to positioning rare diseases as an international health priority.
- **July 2019** saw rare diseases well detailed in a [UN High Commissioner for Human Rights report](#) as one of the essential vulnerable populations on the implementation for UHC.

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About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 800 rare disease patient organisations from over 70 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.

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