

Statement

Patient leaders from global rare disease community meet with Dr Tedros, Director-General of the WHO, to discuss future collaboration



18 March 2019, Geneva - Today, Yann Le Cam, Chief Executive Officer of EURORDIS-Rare Diseases Europe, and Durhane Wong-Rieger, Chair of the Council of Rare Diseases International and President of the Canadian Organization for Rare Disorders, met with Dr Tedros, Director-General of the World Health Organization (WHO), to discuss **a shared vision for the more than 300 million people living with a rare disease across the world.**

Together, Rare Diseases International (RDI), the global alliance of people living with a rare disease, and EURORDIS, an alliance of over 800 rare disease patient organisations, have been advocating over the last two years to make rare diseases a global health priority at the WHO.

EURORDIS and RDI identified areas of collaboration with the WHO to shape a partnership, which will be formalised in a Memorandum of Understanding. This collaboration will set out ambitious goals that contribute to the WHO's 13th General Programme of Work (GPW).

Transformative progress

In 2018 Dr Tedros released a [statement of support](#) in which he called for universal health coverage to include diagnosis and treatment for rare diseases, so as to provide for **a world in which no one is left behind**, including people living with a rare disease. At this point, he welcomed future opportunities for further discussion with the rare disease community on how to strengthen cooperation to ensure people living with a rare disease can access the health services they need.

Mr Le Cam, who is also a member of the RDI Council and Chair of the RDI Advocacy Committee, commented, **“We thank Dr Tedros and his WHO leadership team for their support for the rare disease community. One year on from his statement, we are pleased to meet with him to discuss next steps that the WHO and rare disease community can take to move towards our proposed collaborative framework within the context of the 2030 Sustainable Development Agenda and the WHO GPW 2019-2023. His continued commitment sends a strong message of support to patients around the world. We are also asking the WHO to support our call for the integration of rare diseases into universal health coverage (UHC).”**

Today’s meeting follows the recent Rare Disease Day Policy Event at the United Nations’ New York Headquarters, at which EURORDIS, Rare Diseases International and the NGO Committee for Rare Diseases [called for](#) the integration of rare diseases into the upcoming landmark UN political declaration on 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 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 50 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.

Contact

Eva Bearryman, Communications Manager, EURORDIS-Rare Diseases Europe
eva.bearryman@eurordis.org