



– PRESS RELEASE –

Rare Disease Day 2019 Policy Event at the United Nations: NGO Committee for Rare Diseases calls for a UN resolution on rare diseases

21 February 2019, New York – At today's Rare Disease Day 2019 Policy Event held at the United Nations (UN), the [NGO Committee for Rare Diseases](#) is launching a call for:

- The **integration of rare diseases into the upcoming landmark UN political declaration on universal health coverage (UHC)**, and
- **A UN resolution on rare diseases.**

Organised by the NGO Committee co-founders (Ågrenska and EURORDIS-Rare Diseases Europe) and Rare Diseases International, this is the second high-level event of the NGO Committee for Rare Diseases and takes place to mark the occasion of [Rare Disease Day 2019](#) (28 February).

Anders Olauson, Chair of the NGO Committee and Chairman of Ågrenska (Sweden), said, **“We must ensure that the rights of people living with a rare disease are respected and that we are not discriminated against because patient population numbers seem small for each rare disease. In total, there are 6,700 rare diseases forming a community of over 300 million people.”**

Yann Le Cam, Chief Executive Officer of EURORDIS, stated, **“Today is a crucial step towards the integration of rare diseases into the upcoming UN political declaration on UHC and towards our end goal of a UN resolution on rare diseases. We call on the UN to adopt a resolution at the General Assembly that will formally make rare diseases a global priority, setting in motion a wave of policy actions that will ultimately improve the lives of the over 300 million people affected by rare diseases around the world, and in turn contributing to the achievement of the Sustainable Development Goals and the ambition to leave no one behind.”**

Discussions at the event are focusing on the need to integrate rare diseases into the upcoming landmark UN political declaration on UHC, due to be adopted at the first-ever UN High-Level Meeting on UHC during the UN General Assembly in September 2019. To this end, the NGO Committee is supporting a new position paper from Rare Diseases International that will serve to meet this objective.

Speakers at today's event include, among [many others](#):

- Mr Andrew Gilmour, Assistant Secretary-General for Human Rights and Head of the Office of the High Commissioner for Human Rights in New York
- Dr. Nata Menabde, World Health Organization NYC Office Director
- Dr. Ruediger Krech, Director, Universal Health Coverage and Health Systems, World Health Organization
- Mr Martin Seychell, Deputy Director-General for Health and Food Safety, DG SANTE, European Commission
- Dr. Irene Norstedt, Acting Director responsible for the Health Directorate within the Directorate-General for Research and Innovation, European Commission and Head of Unit, Innovative and Personalised Medicine Unit
- Mr Anders Nordström, Ambassador Global Health, Swedish Ministry of Foreign Affairs.

Ambassadors and officials from the Permanent Missions to the UN of **Brazil, Estonia, France, Japan, Kuwait, Romania, Spain, Thailand**, and the **United Arab Emirates** are also giving official statements linked to today's event.

[See full event programme.](#)

Today's event is held under the patronage of HRH The Grand Duchess of Luxembourg, hosted by the **Permanent Mission of Estonia to the United Nations** and co-hosted by 14 Permanent Missions from: **Belgium, Brazil, Cyprus, France, Japan, Kuwait, Luxembourg, Malta, Romania, Serbia, Spain, Sweden, Thailand, and the United Arab Emirates.**

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[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 the Conference of NGOs in Consultative Relationship with the United Nations \(CoNGO\)](#)

[CoNGO's](#) vision is to be the primary support and platform for a civil society represented by a global community of informed, empowered and committed NGOs that fully participate with the UN in decision-making and programs leading to a better world, a world of economic and social justice. Its mission is to facilitate the development of a dynamic and informed world-wide NGO community able to influence policies and actions at all levels of the United Nations.



About Ågrenska

[Ågrenska](#) is a national centre of competence in Sweden, providing programs for children and adults with disabilities, their families and for professionals supporting the family. Striving to be a progressive and creative meeting place between needs and knowledge, the aim of Ågrenska is to help people to cope with everyday life and to empower them to become as independent as possible.



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 Rare Disease Day

A patient-led campaign, [Rare Disease Day](#) was launched by EURORDIS and its Council of National Alliances in 2008 and brings together millions of people in solidarity. Rare Disease Day takes place on the last day of February each year to raise awareness of the impact that rare diseases have on over 300 million people around the world. Rare Disease Day 2019 is on 28 February. Events and activities will take place in 90+ countries around the world.



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