

**Rare Disease Day Policy Event at the United Nations:  
2<sup>nd</sup> High Level Event of the NGO Committee for Rare Diseases  
21<sup>st</sup> February 2019**



The NGO Committee for Rare Diseases co-founders, Ågrenska and EURORDIS–Rare Diseases Europe, with Rare Diseases International (RDI), would like to thank all participants who followed, in person or online, this second high–level event marking the occasion of Rare Disease Day 2019 which took place at the United Nations Headquarters in New York.

The presentation materials, video recordings of the sessions as well as official photographs are now available online for you to access. Visit our [website](#) for these and have a look below for the highlights of that momentous day!

### Who co-hosted?



The event was 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.

## Who was there?

This all-day roundtable brought together more than 100 participants – from the international NGO community, UN agencies and national governments, academic and research institutions as well as the private sector – interested in collaborating towards the advancement of rare diseases as a global public health priority within the United Nations. **Speakers at the event included, 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



Mr Martin Seychell, Deputy Director-General for Health and Food Safety, DG SANTE, European Commission



Dr. Nata Menabde, World Health Organization NYC Office Director



Dr. Ruediger Krech, Director, Universal Health Coverage and Health Systems, World Health Organization



Mr Anders Nordström, Ambassador Global Health, Swedish Ministry of Foreign Affairs



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

Ambassadors and officials from the Permanent Missions to the UN of Brazil, Estonia, France, Japan, Kuwait, Romania, Spain, Thailand, and the United Arab Emirates also gave official statements during the event.

[See the full programme here](#)

## Highlights

### Rare Diseases within the United Nations Sustainable Development Goals

This event formed part of the broad strategy of the NGO Committee to work towards the achievement of Agenda 2030 and the relevant Sustainable Development Goals that will contribute to better lives for the community of people living with a rare disease.



**Robert Hejdenberg**, Chief Executive Officer of Ågrenska Foundation, highlighted that rare diseases do not only pertain to SDG number 3, i.e. the SDG on health. Indeed, *"the symptoms of a rare disease lead to complex consequences that go far beyond the strictly medical situation, affecting many different areas of a person or a family's life"*. As a consequence, *"the individual requires support by different parts of society: healthcare, labour, social care, school, insurance"*.



Presentations throughout the day solidified the clear alignment between rare diseases and a number of the goals, and the 2030 Agenda's guiding principle "to leave no one behind".

**H.E. Sven Jürgenson**, Ambassador and Permanent Representative of Estonia to the United Nations



*"We must keep in mind that our main goal should be that of Agenda 2030 – that is the imperative of leaving no one behind, which, by definition, also includes leaving no person living with a rare disease behind. 2030 Agenda is for all people, and our work here is to ensure that we will live up to this precious promise."*

**Leslie Wade**, Chief, Inter-organizational and Inter-Institutional Support Branch, UN Department of Economic and Social Affairs

*"The lack of adequate investment in research and innovation, access to diagnostics, medicines and treatments for the 6000 conditions that are considered rare is a clear threat to the principle of leaving no one behind."*



## **Commitment towards the integration of Rare Diseases within Universal Health Coverage**

The event served as a platform to show how the aspirations and objectives behind Universal Health Coverage (UHC) apply to the daily experience, needs and expectations of persons living with a rare disease. In fact, discussions at the event focused on the need to integrate rare diseases into the upcoming landmark UN Political Declaration on UHC, due to be adopted at the first ever 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. **Key ambassadors and UN officials gave encouraging statements on this issue on the day:**

**Andrew Gilmour**, Assistant Secretary-General for Human Rights and Head of the Office of the High Commissioner for Human Rights in New York

*"The exclusion of rare diseases and conditions from medical coverage schemes is a violation of the right to health. As Member States move to seek consensus on a Political Declaration on UHC later this year, we need to ensure*



*that rare diseases are covered and that people living with them benefit from this protection.”*

**H.E. Vitavas Srivihok**, Ambassador and Permanent Representative of Thailand to the United Nations

*(Co-facilitator of informal consultations with Member States ahead of UHC High-Level Meeting)*



*“We must work together to ensure an equitable and affordable access to quality health services and medicines for everyone, especially people who are most in need, which also includes people living with rare diseases, among others, while ensuring that they do not face financial hardship or fall back into poverty because of their catastrophic medical expenses.”*

**H.E. Toshiya Hoshino**, Ambassador and Deputy Permanent Representative of Japan to the United Nations

*“UHC embodies the notion of ‘No One Left Behind’, the core principle of the SDGs, and underpins the concept of human security, which Japan fundamentally subscribes to. In that regard, we will not have achieved Universal Health Coverage unless and until we ensure that persons with rare diseases are not left behind.”*



**Dr. Nata Menabde**, World Health Organisation NYC Office Director



*“We need to secure that as we move to the GA HLM in September, we are making sure that rare diseases are finding their deserved place in these conversations and in the commitments that each head of state will hopefully make. WHO stands by you with this commitment and we will be as always making sure that this issue is not forgotten.”*

## **Call for a UN Resolution on Rare Diseases**

The event launched a call for 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 persons affected by rare diseases around the world.

**Yann Le Cam**, Chief Executive Officer of EURORDIS–Rare Diseases Europe and member of the Council of RDI and of the Board of the NGO Committee for Rare Diseases issued the call on behalf of these bodies, *“which are the expression of civil society on rare diseases within ECOSOC and the UN system, acting as proxies of the 300 million living with a rare disease”*.



He said: *“The objective is to achieve **inclusion and participation of people living with a rare disease and their families in society**; to achieve well-being and optimal health, if not good health; to improve health and social outcomes with the appropriate care within existing resources” and “last but not least, **regular reports by the UN Secretariat to monitor the progress on the implementation so that we know where we are going and what has been achieved”**”.*

**Durhane Wong-Rieger**, Chair of the Council of Rare Diseases International, made clear that the rare disease community is not coming to the United Nations empty-handed. It is coming *“with **tools, plans, strategies”** and most of all, **“with a lot of people who are personally very committed”**”.*

The hope is to work towards this UN Resolution in the coming years, fostering a favourable environment within the United Nations system to ensure the maximum support from Member States and international institutions. **Notable speakers in the audience issued statements amenable to this process:**

**H.E. Ion Jinga**, Ambassador and Permanent Representative of Romania to the United Nations  
*(on behalf of the Romanian EU Presidency)*

*“Our vision is that in order to meet the needs of the rare disease community, it is absolutely necessary to develop, adopt and implement national plans in this field.”*



**Daniela Bas**, Director of Division for Inclusive Social Development, UN Department of Economic and Social Affairs (DESA), United Nations Secretariat



*“Member States with the support of International Organisations need to make their social protection systems more inclusive to accommodate the needs of their citizens, that is also of persons living with rare diseases, guaranteeing that they and their families do not fall into poverty.”*

**Saud Al Shamsi**, Deputy Permanent Representative of the United Arab Emirates to the United Nations

*“The UAE fully supports elevating the issue of rare diseases in the UN Agenda. We all heard the call for a UN resolution on rare diseases and, as a Member State, we could ask the experts to give us something to work on. We should not*



*only encourage the national level policies but also, and more importantly, the UN system must not leave behind people with rare diseases."*

**H.E. Carmelo Inguanez**, Ambassador and Permanent Representative of Malta to the United Nations



*"Malta stands ready with you, and with all Member States, to motivate others to come on board and work for this noble cause so that truly no one will be left behind."*

## What happened on Social media?

There was a lot of activity on Twitter, Facebook and LinkedIn before, during and after the event. Take a look at the [social media impact report here](#).



## A big thank you to all

We would like to thank all participants to the Rare Disease Day Policy Event. The presence of such a heterogeneous group of people and the fruitful exchange of knowledge and ideas made the day a success.

Although the challenges are still many, the rare disease community is strong and ready to make its voice heard globally!

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