Side-event during the High-Level Political Forum (HLPF) 2021

Concept Note

On the road towards COVID-19 recovery and delivery of the SDGs: Addressing the challenges of persons living with a rare disease as a human rights, sustainable development and equity priority.

Date: July 7 2021
Time: 8.00 – 9.30 EDT (New York) / 14.00 – 15.30 CET (Paris)
Co-Sponsors: Permanent Missions of Spain, Brazil and the State of Qatar to the UN, NGO Committee for Rare Diseases, Rare Diseases International, EURORDIS-Rare Diseases Europe

Overview: The 300 million persons living with a rare disease around the world and their families face common challenges in all aspects of their daily lives. As they experience different levels of vulnerability, they are disproportionally affected by stigma, discrimination and marginalization, within their own social environment and in society at large. Knowledge and information are scarce and expertise is not accessible. Stigma, discrimination, lack of awareness and recognition lead to specific challenges in access to education, healthcare, employment and leisure. The impact is felt throughout their lives, causing increased impoverishment and isolation for individuals and their families. These socioeconomic challenges have been worsened by the current Covid-19 pandemic and will not diminish post-COVID-19 unless specific attention is paid to them. In the context of the decade of action and delivery for sustainable development, it is critical to acknowledge how the specific challenges of persons living with a rare disease are at the heart of the 2030 Agenda and present many synergies with the Sustainable Development Goals (SDGs), including goals 1, 3, 8 and 10, which are under review at the High-Level Political Forum 2021. Persons living with a rare disease therefore require immediate and urgent attention, under the auspices of global and national policies that address their needs and respect their human rights. Indeed, unless persons living with a rare disease are explicitly included we cannot ensure that 'no one is left behind.'

Objective of the event: The side-event to the High Level Political Forum 2021 has the objective to showcase how addressing the challenges of persons living with a rare disease, recognising their rights, needs and priorities, as well as promoting their active participation, and harnessing the opportunities for their inclusion in society is essential to the realisation of the 2030 Agenda and to the sustainable recovery from the COVID-19 pandemic. The rare disease civil society community (represented by the NGO Committee for Rare Diseases, Rare Diseases International and EURORDIS-Rare Diseases Europe) with the support of a number of UN Member States including Spain, Brazil and the State of Qatar, proposes to discuss, at the event, the adoption of a UN General Assembly Resolution that can act as a catalyst and provide a constructive and consensual intergovernmental vision on the issue.

Background

The more than 300 million persons living with one of over 6000 identified rare diseases – often chronic, complex, heavily disabling and life threatening – deserve recognition and visibility within the UN's agenda towards inclusive sustainable development. This has been recognised by a number of UN Member States and agencies and bodies (WHO, UNICEF, UNDP, ECOSOC) at the two High Level Events of the NGO Committee for Rare Diseases. First in 2016, at the 'Global Gathering for Rare Diseases' and then in 2019 at the Second High Level Event organised to mark the occasion of Rare Disease Day and co-hosted by 15 Member States. The main synergies between the rare disease community's needs and goals and those of the Sustainable Development Goals include:

The **entire family** is impacted by the challenges of living with a rare disease, causing overall **increased isolation and impoverishment.**

Persons living with a rare disease **lack access to appropriate diagnosis and lifelong care and social support** which are essential to an individual's well-being.

Persons living with a rare disease face **challenges in accessing education at all stages of their life** due to inaccessibility of facilities and non-adapted teaching methods that do not consider their specific needs.

Women living with a rare disease face **more difficulties in accessing care** and, when a member of the family lives with a rare disease, **the primary unpaid care role is most often assumed by women**.

Persons living with a rare disease and their families face **challenges in access, retention and return to employment** due to factors such as non-adapted work environment or timetables, and lack of understanding or flexibility from employers.

The **disproportionate level of vulnerabilities** means persons living with a rare disease and their families face **stigma, discrimination and lack of opportunities for inclusion in society.**

Indeed, **living with a rare disease has an impact on all aspects of a person's life**, including the social, economic, health, educational and employment dimensions. This means that the issue is not only a **sustainable development and equity priority**, but it also represents a **human rights priority**.

In fact, the 2018 Report of the Special Rapporteur on the rights of persons with disabilities to 73rd Session of the UNGA Member States were encouraged to consider developing and implementing policies and practices targeting the most marginalized groups of persons with disabilities such as persons living with a rare disease. And the 2019 Report of the United Nations High Commissioner for Human Rights to the session of the ECOSOC recognised the need to protect the rights of persons living with rare diseases as a particularly vulnerable population.

The time to act is now as the COVID-19 pandemic has magnified inequities. The report on the State of Universal Health Coverage Commitment developed by UHC2030 confirms that the COVID-19 pandemic has disproportionally impacted persons living with a rare disease. Evidence from representative civil society organisations shows that their challenges have been multiplied, with access to care, opportunities for employment and inclusion, and mental and physical well-being severely affected:

- Overall impoverishment of families has increased. Family members (3 in 10) have had to stop working or reduce their working hours because of the loss of support from extended family and friends, and lack of access to social services and benefits.
- Persons living with a rare disease have experienced disruption in access to care (9 in 10), with limitations, delays – and even denial – in access to testing, health services, surgeries, rehabilitation therapy, supportive care, and medicines, with at times irreversible consequences.
- Pre-existing challenges in access, retention and return to employment have been exacerbated. Namely, lack of specific accommodations, flexible working arrangements or adapted work environments.

These challenges will not diminish post-COVID-19 unless holistic policies that ensure inclusion of all people in society and protect human rights for all are put in place.

Proposed programme

Moderator: Ms. Durhane Wong-Rieger, Chair, Rare Diseases International (RDI)

8.00 – 8.15	**Welcoming Remarks (pre-recorded videos)**
	Her Majesty Queen Letizia of Spain
	Her Excellency Michelle Bolsonaro, First Lady of Brazil and Her Excellency Damares Alves, Minister for Women, Family and Human Rights of Brazil
8.15 – 8.20	**Keynote Address**
	Mr. Craig Mokhiber, Director of the New York Office, OHCHR
8.20 – 8.35	**Video of 'Dear UN' testimonies**
	Testimonies from the global rare disease community linked to the SDGs
8.35 – 9.10	**Multi-stakeholder panel discussion**
	The value of UN action to address the challenges of persons living with a rare disease and move towards inclusive sustainable development
	Rev. Dr. Liberato C. Bautista, President of CoNGO (Conference of NGOs in Consultative Relationship with the United Nations)
	Ms. Maria Montefusco, Chairperson of Rare Diseases Sweden and member of the Board of EURORDIS
	Dr. Lucia Monaco, Chair of the International Rare Diseases Research Consortium (IRDiRC)
	Dr. Gareth Baynam, Director of Western Australia's Undiagnosed Diseases Program
9.10 – 9.25	**Q&A from the audience**
9.25 – 9.30	**Closing Remarks**
	Mr. Anders Olauson, Chair, NGO Committee for Rare Diseases