



RARE
DISEASES
INTERNATIONAL



Press Release

Rare Diseases at the United Nations

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

New York, 7 July - In the context of the actions and delivery for sustainable development, a Side-Event to the UN High-Level Political Forum on Sustainable Development (HLPF) was held today, and discussed how addressing the challenges faced by persons living with a rare disease advances the UN 2030 Agenda and the commitment to “Leave No One Behind”.

The event was attended by over 300 participants from 61 countries across the globe, and was opened by Her Majesty Queen Letizia of Spain, and Their Excellencies Michelle Bolsonaro, First Lady of Brazil, and Damares Alves, Minister for Women, Family and Human Rights of Brazil.

Organized on the margins of the HLPF, the side-event was co-hosted by Brazil, Spain and Qatar - the Core Group of Member States promoting the call for a [UN Resolution on Addressing the Challenges of Persons Living with a Rare Disease and their Families](#) - together with the NGO Committee for Rare Diseases, Rare Diseases International and EURORDIS, representing civil society.

Her Majesty Queen Letizia of Spain assured the audience of her country’s support: “Spain fully supports this UN Resolution which, we trust, will generate the proactive readiness and commitment of all so that rare diseases have a much less painful and much less disabling impact on people’s lives. This is our responsibility”.

About the Side-Event to the UN High-Level Political Forum

Representatives from the UN and from civil society discussed the proposed Resolution and how addressing the challenges of this vulnerable population would advance the Sustainable Development Goals and support the commitment to “Leave No One Behind”.



Advancing SDGs 1, 3, 4, 5, 8, 10 and 17 by addressing the challenges of persons living with rare disease and their families.

The proposed UN Resolution promotes full participation and inclusion in society of all people - including those living with a rare disease – and highlights the need for international collaboration, and improved awareness and visibility within the UN system, programmes and agencies.

Anders Olauson, Chair of the NGO Committee for Rare Diseases, launched a call to action to close the event: “Can we do better and more for persons living with a rare disease? The answer is easy and concrete: Yes, we can send a strong collective message to our community by adopting a UN resolution”.

About the global Rare Disease Community

The 300 million persons worldwide living with one of the over 6000 identified rare diseases are calling for recognition and visibility within the UN system.

This vulnerable community faces common challenges, such as difficulty integrating into educational systems, greater risk of facing financial hardship and job insecurity, inadequate care pathways, as well as exclusion and discrimination. These challenges have only been made worse by the COVID-19 pandemic.

At this moment of crisis, the side-event demonstrates how bold steps can address the challenges experienced by families around the world, and help build more inclusive societies for all.

“Through COVID, many of us are experiencing what it is like to live with a rare disease individually, and as a global community. We have to imagine new ways to serve people’s needs”, **Gareth Baynam, Director of Western Australia’s Undiagnosed Diseases Program**.

Key Quotes from Speakers

“My central message is one of encouragement, and I do so from a deep conviction that your hope to uphold the rights of people living with a rare disease is of central importance to the UN 2030 Agenda and commitment to the SDGs”. **Craig Mokhiber Director of the New York Office of the Office of the United Nations High Commissioner for Human Rights (OHCHR)**

“We in the UN need to acknowledge the rare and humbling occasion of which we are trusted by marginalized and excluded communities to reduce the disproportionate level of vulnerabilities, stigma, and lack of opportunities they experience in their communities and larger society”. **Rev. Dr. Liberato C. Bautista, President of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO)**

“The rare disease community demands the whole of government and society, as well as the whole of the UN and the world to cooperate. We are certain that this UN Resolution would help us to connect the wide range of networks, centers, and individuals needed to progress”. **Maria Montefusco, Chairperson - Rare Diseases Sweden and Member of the Board of EURORDIS**

“A UN Resolution would provide a formidable scenario for IRDiRC activities and outputs to be disseminated, acknowledged and adopted at international, national and local levels”. **Lucia Monaco, Chair of the International Rare Disease Research Consortium**.

For more information, please feel free to contact Hlawulani Mkhabela, RDI Outreach and Engagement manager, hlawulani.mkhabela@rarediseasesint.org