HIGH-LEVEL POLITICAL FORUM
ON SUSTAINABLE DEVELOPMENT

Formal Side-Event to the High-Level Political Forum (HLPF) 2022

BUILDING BACK BETTER FROM COVID-19 AND ADVANCING THE 2030 AGENDA: **ADDRESSING THE CHALLENGES OF PERSONS LIVING WITH A RARE DISEASE AS A GENDER EQUALITY, HUMAN RIGHTS, AND EQUITY PRIORITY.**

06 July 2022 - 7:30-9:00 EDT / 13:30-15:00 CET

CONCEPT NOTE

Location: Online.
Register here. : https://bit.ly/3xNuOKh

Co-Sponsors: Office of the High Commissioner for Human Rights (OHCHR), Rare Diseases International (RDI), Permanent Mission of Spain to the United Nations (UN), NGO Committee for Rare Diseases, EURORDIS-Rare Diseases Europe

OVERVIEW:

The more than 300 million Persons Living With a Rare Disease (PLWRD) worldwide and their families deserve full visibility and recognition within the UN Agenda 2030 for Sustainable Development.

PLWRD face specific consequences associated with the rarity of their condition, including lack of knowledge, research, and expertise. These and other challenges are amplified for women and girls, either as persons with a rare disease themselves, or as (often primary) caregivers. Indeed, women and girls encounter the additional barrier of gender discrimination, both within the health-care system and in society more widely. There is evidence demonstrating that there are substantial delays in getting an accurate diagnosis for women and girls compared to men and boys living with the same rare disease. Also, women are at greater risk of impoverishment since the primary unpaid care role is most often assumed by women. The gendered discrimination experienced by women and girls as PLWRD or as their caregivers has, moreover, been worsened by the COVID-19 pandemic, as health-care systems were strained and the burden of care on women was amplified by lockdowns, school closures, and assistance being discontinued.

This intersectional discrimination acts as a barrier towards SDG 5 (Gender Equality).

OBJECTIVE OF THE EVENT:

This formal side-event to the High-Level Political Forum 2022 has the objective to highlight how women and girls living with a rare disease are disproportionately discriminated against - either as persons with a rare disease themselves, or as a parent and caregiver - and to explore steps to alleviate this discrimination. In this context, the rare disease civil society community (represented by Rare Diseases International, the NGO Committee for Rare Diseases, and EURORDIS-Rare Diseases Europe), with the support of the Office of the High Commissioner for Human Rights and the Permanent Mission of Spain to the UN, will discuss how recognizing and addressing this additional intersectional factor of discrimination faced by women can promote SDG 5 of Agenda 2030 and the recovery from the COVID-19 pandemic, Building Back Better and inclusive societies, while also supporting the implementation of the UN Resolution on “Addressing the challenges of PLWRD and their families”.

ABOUT RDI:

RDI is the global alliance of Persons Living with a Rare Disease and their families across all countries and across all rare diseases. RDI is a network of 85 organizations representing patient groups active in over 150 countries worldwide.

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5 GENDER EQUALITY

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AGENDA

7:30-7:40

Opening Remarks: Applying a gender equality, human rights, and equity-centered approach to address the challenges of PLWRD

- **Lynn Gentile**, Office of the High Commissioner for Human Rights (OHCHR), Human Rights and Economic and Social Issues Section

7:40-7:55

Keynote Address

- **Ana Peláez Narváez,** Vice President of the UN Committee on the Elimination of Discrimination Against Women (CEDAW)

7:55-8:45

Panel Discussion from Different Perspectives

- **Baiba Ziemele,** Coordinator of Patient Organisations Network at the Latvian Alliance of Rare Diseases - Latvia
- **Nthabeleng Ramoeli,** Co-Founder of the Rare Disease Lesotho Association - Lesotho
- **Mousumi Mutsuddi,** SERB-POWER Fellow and Coordinator PMRF at Banaras Hindu University - India
- **Adrian Fisher,** Father to a child living with a rare disease and Professor of Electrochemistry at the University of Cambridge - United Kingdom
- **Karla Ruiz de Castilla,** Director of Asociación de pacientes con enfermedades raras y crónicas (ESPERANTRA) - Peru

8:45-8:55

Key Messages for the Rare Disease Community

- **Durhane Wong-Rieger,** President and CEO of the Canadian Organization for Rare Disorders and Chair of RDI's Council

8:55-9:00

Closing Remarks

- **Flaminia Macchia,** Executive Director of Rare Diseases International (RDI)

UNITED NATIONS HUMAN RIGHTS OFFICE OF THE HIGH COMMISSIONER

MISIÓN PERMANENTE DE ESPAÑA ANTE LAS NACIONES UNIDAS

RARE DISEASES INTERNATIONAL

EURORDIS RARE DISEASES EUROPE

NGO COMMITTEE FOR RARE DISEASES