The Formal Side-Event to the High-Level Political Forum, entitled “Addressing the challenges of persons living with a rare disease as a Gender Equality, Human Rights, and Equity Priority”, highlighted how women and girls living with a rare disease are disproportionately discriminated against - either as Persons Living With a Rare Disease (PLWRD) themselves or as a caregiver to a PLWRD.

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With the support of the Office of the High Commissioner for Human Rights (OHCHR) and the Permanent Mission of Spain to the UN, Rare Diseases International (RDI) and the other Co-Sponsors (NGO Committee for Rare Diseases, EURORDIS-Rare Diseases Europe) enabled experts from around the world to discuss how recognizing and addressing this additional intersectional factor of discrimination faced by women can promote Sustainable Development Goal (SDG) 5 of Agenda 2030 - Gender Equality - and the recovery from the COVID-19 pandemic, while also supporting the implementation of the UN Resolution on “Addressing the challenges of persons living with a rare disease and their families”
“We need to mobilise more political commitments for the protection of the rights of women and girls affected with a rare disease.” - Lynn Gentile, Office of the High Commissioner for Human Rights (OHCHR), Economic, Social and Cultural Rights Section

“We need to strengthen the institutional response to these particular needs of women and girls with rare diseases.” - Ana Peláez Narváez, Vice President of the UN Committee on the Elimination of Discrimination Against Women (CEDAW)

“It is not enough to get rid of stigma and discrimination against women, but we do have to move to equity. It would include having the same outcomes for men and boys as for women and girls with a rare disease. It is a human rights issue. Can we actually get to leave no one behind if we do not explicitly address the gender issue?” - Durhane Wong-Rieger, President and CEO of the Canadian Organization for Rare Disorders and Chair of RDI’s Council

“We need to harmonize and improve diagnostic possibilities and access to treatment globally, but the first step is recognition of our issues and the fact that women bleed too.” - Baiba Ziemele, Chairwoman of the Board at the Latvian Alliance of Rare Diseases and at the Latvia Hemophilia Society - Latvia

“We, as rare diseases warriors, face a lot of discrimination. There’s also already unfortunate discrimination for just being a woman, but being a young woman with a rare condition adds even more to the difficulty of making our voice heard!” - Nthabeleng Ramoeli, Co-Founder of the Rare Disease Lesotho Association - Lesotho

“We, as individuals as well as a society, are deeply concerned that the coronavirus pandemic has enhanced the existing inequalities, and those at particular risk are women and girls, and they are in an increasingly vulnerable situation. We urgently need to eliminate the barriers preventing the participation of individuals affected with a rare disease in every walk of life.” - Mousumi Mutsuddi, SERB-POWER Fellow and Coordinator PMRF at Banaras Hindu University - India

“There are not so many male advocates, not because they don’t want to stand up, but because day to day the responsibility and caring fall heavily on mothers whether that’s cultural, whether that’s societal, whether that’s practical.” - Adrian Fisher, Father to a child living with a rare disease and Professor of Electrochemistry at the University of Cambridge - United Kingdom
"In the case of women suffering from a rare disease, we have observed that they have greater difficulty working towards a career or even exercising a career. Therefore, women as a group are vulnerable and not included in many aspects of society. This is a very important issue." - Karla Ruiz de Castilla, Director of Asociación de pacientes con enfermedades raras y crónicas (ESPERANTRA) - Peru

"We now need to strengthen the global response and develop concrete policies based on disaggregated data. This call is included in the recently adopted UN Resolution on “Addressing the challenges of persons living with rare diseases and their families”.
- Flaminia Macchia, Executive Director of Rare Diseases International (RDI)

"Women and girls living with a rare disease or those that act as their caregivers are entitled to full and unabridged access to Universal Health Coverage. This event has furthered the discussion. We need to take this far.” - Dolores Cvitićanin, Public Affairs Manager of Rare Diseases International (RDI)

KEY NEXT STEPS

- Recognize gender equality issues for PLWRD or their caregivers as a human rights priority
- Address the effects of the COVID-19 pandemic, which have worsened gender discrimination
- Contribute to data and reporting on intersectional discrimination for PLWRD
- Strengthen the institutional response and develop concrete policies to alleviate this discrimination

290+
REGISTERED

160
ATTENDEES connected live to the digital platform

60+
VIEWS of the recording within one week of the event

WATCH THE REPLAY