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PRESS RELEASE

Civil Society Organisations and Policy Makers Call for an Equitable Future for the over 300 Million Persons Living with a Rare Disease Worldwide.

Stakeholders from over 90 countries gathered at EXPO Dubai to mark the adoption of the ground-breaking UN Resolution on “Addressing the Challenges of Persons Living with a Rare Disease and their families” and develop a common roadmap for the Resolution’s implementation.

[Brussels / New York], 28 February 2022 - On the occasion of Rare Disease Day 2022, the NGO Committee for Rare Diseases, Ågrenska Foundation, Rare Diseases International (RDI), and EURORDIS-Rare Diseases Europe, hosted a high-level policy event at EXPO Dubai 2020.

Entitled ‘*Rare Diseases – A Global Priority for Equity*’, the event marks the first major gathering of the global rare disease community since the adoption of the historic UN Resolution. It convened stakeholders to discuss how this important milestone could drive greater equity and ensure that PLWRD around the world have the same opportunity to live to their fullest potential, access timely diagnosis, and receive appropriate health and social care.

By placing the challenges of the community on the global stage offered by EXPO Dubai, civil society partners hope to strengthen national and regional rare disease advocacy and give full visibility and recognition to this vulnerable population.

PLWRD form a global population of over 300 million people living with one of the over 6,000 identified rare diseases. The rarity of each condition means that the medical community, policy makers and society lack awareness and understanding of the specific challenges of those living with a disease that is rare.

“Indifference and invisibility enable multiple and intersecting forms of discrimination and inequity. The visibility offered by this resolution is of paramount importance” - says Flaminia Macchia, RDI Executive Director.

PLWRD face challenges related to health and wellbeing as well as social barriers including difficult access to quality education and work, greater risk of poverty, and social stigma. As most rare diseases begin in childhood, inequities are felt from a young age and throughout a lifetime by PLWRD, their families and loved ones.

On 16 December 2021, the rare disease community reached a historic milestone, with the UN General Assembly adopting a Resolution on PLWRD and their families. The text focuses on the principles of equity and non-discrimination and advances key pillars of the UN Sustainable Development Goals (SDGs), including access to education and decent work, reducing poverty, tackling gender inequality, and supporting participation in society.



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“A decade ago, the term ‘rare diseases’ did not feature in UN documents, and now we have a powerful message of support and recognition in the form of a Resolution adopted by consensus by all 193 UN Member States” - says Anders Olauson, Chair of the NGO Committee for Rare Diseases”

However, more must be done on a global, regional, and local level to support diagnosis, strengthen health systems to meet the needs of the community, and identify social services that reduce the societal and financial impact of living with a rare disease.

The event launches an international advocacy campaign calling for concrete measures to promote health equity and Universal Health Coverage to address rare diseases. The community now demands coordinated action from UN agencies and national governments to promote a more equitable future for PLWRD and their families.

Key Quotes

“You can count on our support to take this historic milestone to the next level globally and in efforts towards the implementation of the resolution at regional and national level” - Agustín Santos Maraver, Permanent Representative of Spain to the United Nations

“This resolution should open doors for Persons Living with a Rare Disease to demand equity and call for action from the UN, regional institutions and national governments.” - Yann Le Cam, CEO EURORDIS - Rare Diseases Europe

“We at the WHO are so very pleased to see this resolution as it contains strong language on how health systems can be strengthened and the need to advance on Universal Health Coverage” - Ruediger Krech, Director, Health Promotion Department, World Health Organisation