

PRESS RELEASE

First-ever United Nations Resolution to Increase Visibility for the 300 Million Persons Living with a Rare Disease

A global grassroots campaign led by persons living with a rare disease and their families has succeeded in securing the adoption of the first-ever UN Resolution on “Addressing the Challenges of Persons Living with a Rare Disease and their Families.”

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– Rare Diseases International (RDI), the NGO Committee for Rare Diseases, and EURORDIS-Rare Diseases Europe announced today that the UN General Assembly formally adopted a resolution recognizing the over 300 million Persons Living with a Rare Disease (PLWRD) worldwide and their families.

The Resolution focuses on the importance of 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.

Adopted by consensus by the 193 UN Member States

The Resolution, proposed by Spain, Brazil, and Qatar and co-sponsored by 54 countries, was adopted by consensus with the support from all 193 UN Member States of the General Assembly. This follows the UN Third Committee’s adoption of a ground-breaking text as part of its agenda on Social Development and is a significant turning point that places the rare disease community firmly on the agenda of the UN.

“Addressing the specific challenges faced by Persons Living with a Rare Disease is a necessary step toward making this vulnerable population visible and contributing to the UN Agenda 2030 SDGs,” said Flaminia Macchia, Rare Diseases International Executive Director. “The consensus in support of the Resolution sends a clear message that Leaving No One Behind is a priority for the UN”.

Presenting the proposal to the UN Third Committee, Maria Bassols, Deputy Permanent Representative of Spain to the UN, affirmed on behalf of the Core Group of Member States

that " Persons Living with a Rare Disease are at greater risk of stigmatisation, as well as intersecting forms of discrimination that are obstacles to their full participation in society".

The global, landmark campaign for equity that achieved the Resolution was the outcome of coordinated and tireless advocacy led by civil society partners, including the NGO Committee for Rare Diseases, RDI, and EURORDIS, and engages national rare disease groups active in over 100 countries. The civil society partners worked to frame the needs of PLWRD beyond health and to illustrate the holistic impact of life with a rare disease on the whole family.

The impact of the Resolution

This first Resolution on PLWRD represents a major shift in the global policy landscape, promising greater integration of rare diseases in the agenda and priorities of the UN system.

"This UN Resolution within the 2030 Agenda and its SDGs is a supportive global framework to encourage regional policy and action. In the European Union, it should translate into a Europe's Action Plan for Rare Diseases," said EURORDIS-Rare Diseases Europe's Chief Executive Officer, Yann Le Cam.

Anders Olauson, Chair of the NGO Committee, stated: "The UNGA Resolution illustrates the power of the global community. Individually, rare diseases are rare, but together PLWRD constitute a significant community deserving of UN support and recognition. Together, we are a powerful and inspirational voice."

Civil society partners are now working to approach the World Health Organization (WHO) to continue the momentum from this historic achievement and call for a resolution that focuses on health equity and strengthening care systems for PLWRD.

Additional Information

About rare diseases

- There are over 300 million PLWRD worldwide.
- There is a lack of public awareness of rare diseases which results in greater risk of social exclusion and multiple forms of discrimination against PLWRD.
- There are over 6,000 identified rare diseases, most of which start in childhood.
- Rare diseases are often chronic, progressive, and frequently life-threatening.

About the civil society partners

☒ The NGO Committee for Rare Diseases is a substantive committee established under the umbrella of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO). It aims to promote collaboration and actions for PLWRD within the UN.

☒ Rare Diseases International (RDI) is the global alliance of PLWRD and their families. RDI is a network of 81 organisations representing groups active in over 100 countries worldwide.

☒ EURORDIS-Rare Diseases Europe is the alliance of 984 rare disease patient organisations that work together to improve the lives of the 30 million PLWRD in Europe and beyond.

