

PRESS RELEASE

Global call for a UN Resolution to protect and promote the human rights of the 300 million people living with a rare disease worldwide

The global community of persons living with a rare disease, their families, and civil society organisations, with the support of UN Member States, are calling for the adoption of a UN Resolution Addressing the Challenges of Persons Living with a Rare Disease and their Families.

28 April 2021 – The global rare disease community - represented by the NGO Committee for Rare Diseases, Rare Diseases International (RDI) and EURORDIS - is **urging UN Member States to recognise the specific challenges of persons living with a rare disease and adopt measures that promote inclusion in society and protect the human rights of all people, including PLWRD.**

More than 300 million people worldwide live with one of over 6000 identified rare diseases. Rare diseases are often chronic, complex, heavily disabling and life-threatening. No matter where in the world they live, PLWRD are faced with the same common challenges. The general lack of public awareness and expertise constraints mean that PLWRD and their families are not prioritised and are neglected in national health systems and social policies.

PLWRD and their families are at the margins of society: they experience discrimination and face difficulties accessing health care, education, employment and leisure. The impact is felt throughout the lifetime, with a detrimental effect on their participation in society, causing increased impoverishment and isolation. **Addressing these common challenges should be a human rights and social equity priority.**

A growing group of UN Member States including Brazil, Spain and Qatar, are championing the call for the adoption of the UN General Assembly Resolution in 2021. They recognise that the Resolution would strengthen the global human rights agenda and significantly advance the UN Sustainable Development Goals (SDGs) rooted in the commitment to “leave no one behind”. The community is urging all 193 Member States of the General Assembly to join the call, and adopt the Resolution this year.

Durhane Wong-Rieger, RDI Chair and President of the Asia Pacific Alliance of Rare Disease Organisations, affirms the urgency of this call, saying: “The COVID-19 pandemic has highlighted the pressing need to address health as well as social and economic inequalities which will not disappear unless specific policies are put in place. The time is now to address the needs of the most vulnerable groups and protect the human rights of all people”.

Why a UN General Assembly Resolution?

A UN General Assembly Resolution is an important step towards global recognition and greater visibility for the community of persons living with a rare disease. It would support international



policies and programmes addressing rare diseases and help to empower national rare disease groups advocating to improve the lives of PLWRD and their families.

How to support the call for the UN Resolution?

Every voice matters. We call on the public, civil society groups, governments and all interested parties to join the call for the UN Resolution to be adopted before the end of 2021. The three partner organisations are launching the [#Resolution4Rare Tools Page](#). The Page features monthly updates including letter templates to reach out to policy makers, infographics as well as posts, images and GIFs to spread the word on social media. **Download advocacy and communication materials, and use the hashtag [#Resolution4Rare](#), today and throughout 2021.**

Additional information

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 multi-stakeholder collaboration and actions for PLWRD within the United Nations system.

[Rare Diseases International](#) (RDI) is the global alliance of PLWRD of all nationalities across all rare diseases. RDI is a network of 78 member organisations representing rare disease patient groups in over 100 countries worldwide. It advocates to make rare diseases an international public policy priority, represents its members on international platforms, and helps members build their capacity to act locally, regionally and globally.

[EURORDIS-Rare Diseases Europe](#) is the alliance of 962 rare disease patient organisations from 73 countries that work together to improve the lives of the 30 million PLWRD in Europe.

More about persons living with a rare disease

- An estimated **300 million persons** are living with a rare disease worldwide.
- There are over **6,000 different rare diseases**, most of which start in **childhood**.
- Rare diseases include **genetic conditions, rare cancers, rare infections and allergies** (bacterial, viral, or caused by factors like food poisoning or chemicals).
- Rare diseases are **chronic, progressive, degenerative, disabling and frequently life-threatening**.

Press Contact

For any questions related to the campaign, please contact Clara Hervas, Public Affairs Manager, RDI/EURORDIS (clara.hervas@eurordis.org).

