**Call for a UN General Assembly Resolution on**

 **Addressing the Challenges of Persons Living with a Rare Disease and their families**

**Template letter for members of Rare Diseases International**

**Instructions for sending this letter:**

* If you would like to send this letter to your national authorities, email **Clara Hervas, Public Affairs Manager (EURORDIS/RDI) to obtain a Word version of the document: clara.hervas@eurordis.org**
* **Target audience:** national authorities, like for example the Ministry of Health, the Ministry of Foreign Affairs, the Ministry of Social Affairs or you Permanent Mission to the UN from your country.
* You may adapt the content of the letter as you please to include your own logo, wording, data, etc., especially if you are not a national alliance.
* Delete this page, add a signature and transform into PDF once edited.
* We recommend attaching the Concept Note of the campaign to this letter (a Word version is available if you wish to translate it).
* **Please inform Clara Hervas of any feedback received from national authorities (positive or negative).**

**Thank you for participating in the Campaign for a UNGA Resolution!**

NAME OF RECIPIENT & ADDRESS

**Subject:** Request for COUNTRY to support the adoption of a UN General Assembly Resolution on Addressing the Challenges of Persons Living with a Rare Disease and their families

Dear [Name]

I am writing to you from [NAME OF YOUR ORGANISATION] the [NAME OF YOUR COUNTRY] national alliance for persons living with a rare disease. More than XXX people are affected by a rare disease in [COUNTRY] and an estimated 300 million in the world.

Most persons living with a rare disease (PLWRD) around the world are at the margins of society, unrecognized, stigmatized, and discriminated. They face a lack of understanding of the multi-dimensional challenges that impact all aspects of their life, beyond just health. **They are a psychologically, socially, culturally and economically vulnerable population, facing discrimination and specific challenges in healthcare, education, employment and leisure.** The impact heavily affects families too and is detrimental to active participation in society, causing increased impoverishment and isolation.

This specific combination of vulnerability, exclusion and inequity is why the challenges of PLWRD need to be positioned as a **human rights issue at the global level,** and need to be addressed within **the UN Agenda 2030: The Sustainable Development Goals (SDGs)**, in line with the principle to “leave no one behind” and the endeavour to reach the furthest behind first.

**To ensure the well-being of PLWRD, it is necessary for Member States of the UN General Assembly to collectively promote measures that are multidisciplinary, holistic and person-centred, and that ensure non-discrimination and opportunities to contribute to society.**

We are encouraged by the attention that PLWRD have progressively been given by our government and an increasing number of other governments worldwide. In addition, the COVID-19 pandemic has highlighted the need to urgently address pre-existing health, social and economic inequalities, which will not disappear post-COVID-19 unless specific policies are put in place. It is our firm belief this is the time to make progress towards the SDGs in our country, to ‘build back better’ and ‘leave no one behind’.

**Together with our international partners – the NGO Committee for Rare Diseases, Rare Diseases International (RDI) and EURORDIS-Rare Diseases Europe – we call upon you to support the adoption of a UN General Assembly Resolution on Addressing the Challenges of Persons Living with a Rare Disease and their families.**

Please find enclosed a Concept Note as well as an infographic on the campaign for a UNGA Resolution with detailed information on the worldwide situation of PLWRD and they ‘Key Asks’ of the community of PLWRD.

We would be happy to arrange a meeting with you or your colleagues, virtually or face to face, to discuss this matter in more detail.

We, as the national alliance of persons living with a rare disease in [COUNTRY], welcome any action you can take to improve the lives of your constituents living with a rare disease.

Sincerely,

[SIGNATURE – President of NA]