

Mr Micheál Martin, TD  
Government Buildings  
Merrion St  
Dublin 2

15<sup>th</sup> December 2021

**Subject:** Thank you to Ireland for co-sponsoring the UN General Assembly Resolution on Addressing the Challenges of Persons Living with a Rare Disease and their families

Dear Taoiseach

Rare Diseases Ireland, the Irish national alliance for persons living with a rare disease, together with our international partners – the NGO Committee for Rare Diseases, Rare Diseases International (RDI) and EURORDIS-Rare Diseases Europe - would like to **express our thanks to you for Ireland’s co-sponsoring of the UN Resolution on Addressing the Challenges of Persons Living with a Rare Disease and their families.**

The global rare disease community was delighted when the Third Committee of the UN General Assembly adopted by consensus the draft proposal. The final resolution is due to be adopted at the UN General Assembly tomorrow, December 16<sup>th</sup> 2021.

This is a momentous occasion for those living with rare diseases and their families in Ireland and around the world. We are very proud that Ireland has supported this initiative. This new resolution encourages holistic and person-centred measures that ensure non-discrimination and opportunities to contribute to society for persons living with a rare disease.

**There are an estimated 300,000 people in Ireland living with a rare disease. Many in the rare community face psychological, social, cultural, and economic challenges on a daily basis, with specific challenges in healthcare, education, employment, housing and leisure.** The COVID-19 pandemic has highlighted the need to urgently address these inequalities, which will not diminish post-COVID-19 unless specific policies are put in place. It is our firm belief this is the time to make progress on your commitments and promises to the rare disease community in the programme for government: Our Shared Future. **We would be happy to arrange a meeting with you to discuss this matter in more detail.**

Once again, thank you very much for Ireland’s co-sponsorship of this UN Resolution. We look forward to working with all arms of government to deliver on your commitments in the programme for government and the wider actions detailed in the UN Resolution. It is our firm belief this is the time to make progress on the core objective: “leave no one behind”.

Sincerely,



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Vicky McGrath  
CEO  
Rare Diseases Ireland