

The Honourable Patty Hajdu
Minister of Health
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Ottawa, Ontario K1A 0K9
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Subject: Request for Canada 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 Minister Hajdu,

I am writing to you from Canadian Organization for Rare Disorders the Canadian national alliance for persons living with a rare disease. Nearly 3 million people are affected by a rare disease in Canada 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'.

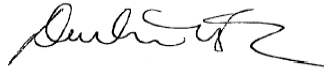
Together with our international partners – the NGO Committee for Rare Diseases, Rare Diseases International (RDI) and EURORDIS-Rare Diseases Europe – we call upon you to support the adoption of a UN General Assembly Resolution on Addressing the Challenges of Persons Living with a Rare Disease and their 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 Canada, welcome any action you can take to improve the lives of your constituents living with a rare disease.

Sincerely,



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