

Join the global community of people living with rare conditions, led by Rare Diseases International, EURORDIS – Rare Diseases Europe and the NGO Committee for Rare Diseases, in calling for a UN Resolution that recognises the complex challenges faced by people living with rare condition, and promotes full participation and inclusion of all people in society.

The National Rare Diseases Office (NRDO), Ireland fully supports the adoption of a UN Resolution addressing the challenges of persons living with rare diseases and their families at the upcoming UN General Assembly.

It is estimated that 300,000 people are affected by rare conditions in Ireland and an estimated 300 million people worldwide. People living with a rare condition face a lack of understanding of the multiple challenges that impact all aspects of their daily lives. They and their families reveal that their needs largely go unheard and unaddressed - lack of clear diagnosis and treatment, lack of co-ordinated and appropriate care, lack of timely access to information, lack of education and employment opportunity.

People living with rare conditions are psychologically, socially, culturally and economically vulnerable, facing discrimination and challenges in healthcare, education, housing, employment and leisure. These challenges affect their families too and are detrimental to active participation in society, leading to increased marginalisation, isolation and impoverishment. The combination of vulnerability, exclusion and inequity is why the challenges of people living with rare conditions need to be positioned as a human rights issue at the global and National level, and need to be addressed within the UN Agenda 2030.

It is our belief that now is the time to make real progress towards Sustainable Development Goals, to 'build back better' following the COVID-19 pandemic and to 'leave no one behind'.

The National Rare Diseases Office, Ireland asks all Member States of the UN General Assembly to collectively promote measures that are multidisciplinary, holistic and person-centred, and that ensure non-discrimination and promote opportunities for all citizens to fully contribute to society.