An Taoiseach
Micheál Martin, TD
Government Buildings
Merrion St
Dublin 2, D02 R583

September 28 2021

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Call for Ireland to support adoption of UN Resolution Addressing Challenges of Persons Living with Rare Diseases & their Families

Dear Taoiseach

We the undersigned are writing to you to ask for Ireland's support for 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 worldwide.

Many people living with rare conditions in Ireland and around the world are at the margins of society, often unrecognized and discriminated against. They face a lack of understanding of the multiple challenges that impact all aspects of their daily lives. Reports from persons living with rare conditions and their families reveal that their needs largely go **unheard and unaddressed** - lack of understanding amongst professionals, 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 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 principle to reach the furthest behind first.

To ensure the well-being of people living with rare conditions, we ask Ireland and 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.

We are encouraged by the attention that the rare community have progressively been given by the Irish government. Publication of the National Rare Disease Plan 2014-2018 was a first step. This has been followed by recognition in the most recent Programme for Government: Our Shared Future. Similar attention has been given by a number of governments worldwide. However commitment to address all the challenges of living with a rare condition on a global basis is required. The challenges of people living with rare conditions and their families must be officially named and acknowledged within our UN constitutional rights.

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

We call upon Ireland to support 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 prepared by our international partners – the NGO Committee for Rare Diseases, Rare Diseases International and EURORDIS-Rare Diseases Europe – with detailed information on the worldwide situation of people living with rare conditions and the 'Key Asks' of the global rare community.

Epilepsy Ireland
FIGHTING BLINDNESS
HRCI Health Research Charities Ireland
HHT ireland
Huntington's Disease Association of Ireland
IRISH EDS & HSD
IPPOSI
ILFA Irish Lung Fibrosis Association
LiamsLodge
MDI MUSCULAR DYSTROPHY IRELAND
nai NEUROLOGICAL ALLIANCE of IRELAND
OACS Ireland

We, as representative organisations supporting the rare community in Ireland welcome any action you can take to improve the lives of the citizens of Ireland living with rare conditions and the lives of those around the world living with rare conditions.

- Anne Lawlor, Chair - **22q11 Ireland**
- Mary Byrne, Advocate - **All Ireland Amyloidosis Support Grp**
- Geraldine Kelly, Chief Executive - **Alpha-1 Foundation Ireland**
- Maureen Sweeney, Administrator - **Ataxia Foundation Ireland**
- Sandra Phair, Chair - **Cavernoma Ireland**
- Shannon Gavin, Advocate - **Childrens Pain Management Advocacy**
- Philip Watt, Chief Executive - **Cystic Fibrosis Ireland**
- Suzanne Dowd, Operations, Advocacy and Policy Officer - **DEBRA Ireland**
- John Dolan, Chief Executive - **Disability Federation Ireland**
- Peter Murphy, Chief Executive - **Epilepsy Ireland**
- Kevin Whelan, Chief Executive - **Fighting Blindness**
- Avril Kennan, Chief Executive - **Health Research Charities Ireland**
- Dara Woods, Director - **HHT Ireland**
- Patricia Towey, Information & Services Coordinator - **Huntington's Disease Assoc of Ireland**
- Anne Micks, Chair - **Irish EDS & HSD**
- Derick Mitchell, Chief Executive – **IPPOSI**
- Eddie Cassidy, Chair - **Irish Lung Fibrosis Assoc**
- Elaine McDonnell, Chief Exec - **Muscular Dystrophy Ireland**
- Magdalen Rogers, Executive Director - **Neurological Alliance of Ireland**
- Karen Keely, Chair - **Organisation Anti-Convulsant Syndrome Ireland**
- Anna Doyle, Advocate - **Peutz-Jeghers Syndrome Awareness**
- Bernadette Gilroy, Chair - **PKU Assoc of Ireland**
- Caroline Dooley Martyn, Director - **PSPA Ireland**
- Vicky McGrath, Chief Executive - **Rare Diseases Ireland**
- Laura Egan, Chair - **Rare Ireland Family Support Network**
- Samantha Jones, Office & Accounts Manager - **The Saoirse Foundation**
- Deirdre McDonnell, Elaine Kelly & Annette Toner, Co founders - **Scoliosis Awareness & Support Ireland**
- Jonathan W O'Grady, Director - **Spinal Muscular Atrophy Ireland**
- Louise Neylin, Secretary - **Syringomyelia Chiari Ireland Group**
- Beth Milofsky, Founder - **SWAN Ireland - Syndromes Without A Name**
- Julie Power, Policy Officer - **Vasculitis Ireland Awareness**

Please contact Rare Diseases Ireland for questions & further information – vicky.mcgrath@rdi.ie

Call for a UN General Assembly Resolution on Addressing the Challenges of Persons Living with a Rare Disease and their families

Concept Note

This note aims to share some context and key messages for the campaign launched by the NGO Committee for Rare Diseases, Rare Diseases International (RDI) and EURORDIS-Rare Diseases Europe and all their members, calling for the adoption a UN General Assembly Resolution on Addressing the Challenges of Persons Living with a Rare Disease (PLWRD) and their families in 2021.

Context

The overarching goal of the campaign is to **recognise that PLWRD are an overlooked population requiring immediate and urgent attention, and global and national policies that address their needs and contribute to achieving the UN 2030 Agenda,** the Sustainable Development Goals and their pledge to 'leave no one behind'.

The rare disease civil society community, with the support of a number of UN Member States including Brazil, the State of Qatar, and Spain, propose to adopt **a UN General Assembly Resolution that can act as a catalyst towards this goal.**

Background:

a) The **300 million PLWRD around the world and their families face common challenges in all aspects of their daily lives.** As a population with increasing vulnerabilities, they are disproportionally affected by stigma, discrimination and social marginalization, within their social environment and in society at large. The paucity of knowledge and expertise on rare diseases and the lack of awareness of the challenges faced by PLWRD mean that **they are psychologically, socially, culturally and economically vulnerable.**

b) There are a number of **synergies between the rare disease community's needs and goals, and those of the UN 2030 Agenda and its Sustainable Development Goals**[1], mainly the following ones:

[1] More information on these can be found in the reports from the 2016 and 2019 high-level events of the NGO Committee for Rare Diseases hosted at the United Nations and hosted by a number of UN Member States

- Challenges affect the whole family and cause overall increased isolation and impoverishment (SDG 1);
- PLWRD lack access to appropriate diagnosis and lifelong care and social support (SDG 3);
- PLWRD face challenges in accessing education at all stages of their life due to inaccessibility of facilities and non-adapted teaching methods (SDG 4);
- Women living with a rare disease face more difficulties in accessing care and, when a member of the family lives with a rare disease, the primary unpaid care role is most often assumed by women (SDG 5);
- PLWRD and their families face challenges in access, retention and return to employment (SDG 8);
- The disproportionate level of vulnerabilities means PLWRD face stigma, discrimination and lack of opportunities for inclusion in society (SDG 10).

UNGA Resolution Initiative

The time to act is now. The COVID-19 pandemic has shed light on pre-existing social, economic and health inequalities between and within countries and demonstrated the urgent need to address the challenges of PLWRD. During the crisis, challenges have been multiplied, with access to care, opportunities for employment and inclusion, and mental health being disproportionately impacted[2]. However, these challenges will not disappear post-COVID-19 unless specific policies for PLWRD are put in place in order to move towards the SDGs and to 'build back better'.

The community of PLWRD is calling for the adoption a UNGA Resolution made up of **5 Key Asks** and **consistent with a range of existing initiatives, policies, and declarations in different areas**, including:

- *Protection of Human Rights*
- *Fight against Stigma, Discrimination, Exclusion, and Marginalization*
- *Disability*
- *Vulnerability*
- *Rights of Children and Rights of Women*
- *Universal Health Coverage*
- *Agenda 2030, Sustainable Development Goals, the commitment to "Leave no one behind"*
- *Social Inclusion*

Key Asks:

1. **Human rights and inclusion: Participation and inclusion of persons living with a rare disease & their families in society and respect of their human rights**

   Encourage Member States:

   - *To uphold the **Human Rights** of all persons, including PLWRD;*
   - *To address root causes of **discrimination** against PLWRD, including through dissemination of accurate information and **awareness-raising activities**, such as proclaiming the last day of February as the annual global Rare Disease Day;*
   - *To collect, compile and disseminate **disaggregated data** on PLWRD to identify **patterns of discrimination** and to assess progress towards improving their status.*

[2] More information at 'To 'Build Back Better' do not leave behind people living with a rare disease in COVID-19 response and recovery'.

2. ***Appropriate care: Improvement of health and social outcomes with the appropriate care and support within existing resources***

   - *Urge Member States to **strengthen efforts to address the challenges of PLWRD within Universal Health Coverage** by implementing interventions, facilitating multidisciplinary care, and promoting equity of outcomes;*
   - *Encourage Member States, the UN system and other stakeholders to support the **networking of experts and centres of care globally - to strengthen healthcare systems and facilitate access** to diagnosis and holistic care, including social care for PLWRD;*
   - *Encourage Member States, the UN system and other stakeholders to **strengthen international collaboration and coordination of research efforts**, as well as **sharing of data** on rare diseases.*

3. ***National strategies: Promotion of national strategies and measures to leave no one behind***

   *Encourage Member States to **adopt / develop:***

   - *National strategies, plans, legislations on the **rights of PLWRD** in conformity with international human rights obligations and commitments;*
   - *Policies and measures to address **social development challenges** faced by PLWRD who may need assistance to access benefits and services (education, employment, healthcare) and promote their participation in society.*

   *Urge Member States to **implement** national measures:*

   - *To ensure PLWRD are **not left behind**, recognizing that they are often disproportionately affected by poverty, discrimination;*
   - *To commit working towards **social integration**, as well as mental and physical well-being of PLWRD.*

4. ***Recognition in the UN system: Integration and visibility of the rare diseases issue into UN agencies and programmes***

   - *Urge Member States, UN Agencies and other relevant international and regional organisations to make a concerted effort – **within the existing resources** - to include PLWRD into **the monitoring and evaluation of the Sustainable Development Goals (SDGs),** in particular SDG 1 on Poverty, SDG 3 on Health, SDG 4 on Education, SDG 5 on Gender Equality, SDG 8 on Decent Work for All, SDG 9 on Innovation, and SDG 10 on Reduced Inequalities;*
   - *Encourage Member States, the UN System and other stakeholders to foster **international cooperation and improve coordination** among existing international processes and instruments to advance an inclusive Global Agenda 2030 and **facilitate cross-learning and sharing of information, practices, tools and resources** that are inclusive and accessible to PLWRD.*

5. ***Monitor progress and implementation: Regular reports by the UN Secretariat to monitor the implementation and progress on the status of PLWRD***

   - *Ask to the Secretary General to present a **Report to the General Assembly on the various social development challenges faced** by PLWRD and measures taken, with **recommendations** for further action to be taken by Member States and other stakeholders **to address identified challenges;***
   - *Encourage the Secretary General **to collect information** from Member States and all relevant organisations and bodies of the UN System and civil society in **preparation of the report**;*
   - *We ask to the UN General Assembly to **consider the issue of PLWRD as part of their Agenda**.*

Additional information

More about persons living with a rare disease

- There are an estimated **300 million persons** living with a rare disease worldwide.
- There are over **6,000 different rare diseases**, most of which start in **childhood.**
- Rare diseases can be **genetic, 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**.

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) and 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 76 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 956 rare disease patient organisations from 73 countries that work together to improve the lives of the 30 million PLWRD in Europe.

Contact Details

For any questions related to the campaign, please do not hesitate to contact Clara Hervas, Public Affairs Manager, RDI/EURORDIS (clara.hervas@eurordis.org).

Visit rarediseasesinternational.org/resolution4rare to find out more.