



Statement by the Undiagnosed Diseases Network International (UDNI) Governing Board

On November 10, 2021, the Third Committee of the 76th Session of the United Nations General Assembly adopted a 5-page Resolution on Persons Living With a Rare Diseases and their families. Selected excerpts include the following:

The General Assembly,

Recognizing the need to promote and protect the human rights of all persons, including the estimated 300 million persons living with a rare disease worldwide, many of whom are children, by ensuring equal opportunities to achieve their optimal potential development and to fully, equally and meaningfully participate in society,

Encourages Member States to address the root causes of all forms of discrimination against persons living with a rare disease, including through awareness-raising, the dissemination of accurate information on rare diseases and other measures, as appropriate;

Encourages Member States and relevant United Nations agencies to collect, analyse and disseminate disaggregated data on persons living with a rare disease, including by income, sex, age, race, ethnicity, migration status, disability, geographical location and other characteristics relevant in national contexts, where applicable, to identify discrimination and to assess progress towards the improvement of the status of persons living with a rare disease;

Encourages Member States to foster the creation of networks of experts and multidisciplinary specialized expert hubs, inter alia, for rare diseases and to increase support for research, by strengthening international collaboration and coordination of research;

Urges Member States to implement, as appropriate, national measures to ensure that persons living with a rare disease are not left behind, recognizing that persons living with a rare disease are often disproportionately affected by poverty, discrimination and lack of decent work and employment.

Calls upon Member States to accelerate efforts towards the achievement of universal health coverage by 2030 to ensure healthy lives and promote well-being for all persons, including those persons living with a rare disease all throughout the life course, and in this regard re-emphasizes the resolve:

(a) To progressively cover persons living with a rare disease with quality essential health products, health services and quality, safe, effective, affordable and essential medicines,

diagnostics, and health technologies, with a view to covering all persons living with a rare disease by 2030;

(b) To stop the rise and reverse the trend of catastrophic out-of-pocket health expenditure by providing measures to ensure financial risk protection and eliminate impoverishment due to health-related expenses by 2030, with special emphasis on persons living with a rare disease.

The UDNI supports this resolution and devotes efforts toward addressing deficiencies in Diversity, Equity, and Inclusion, since individuals with undiagnosed diseases are often excluded from healthcare and social communities. The UDNI does this by attempting to establish Undiagnosed Disease Programs throughout the world and by having a Developing Nations Working Group to promote rare disease diagnosis in developing countries and a Diagnostics Working Group to provide access to undiagnosed disease experts for individuals anywhere in the world.

Effective January 1, 2022 by the UDNI Governing Board.

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