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[*on the report of the Third Committee (A/80/545, para. 5)*]

80/176. Addressing the challenges of persons living with a rare disease and their families

The General Assembly,

Recalling the Universal Declaration of Human Rights,[1] the International Covenant on Economic, Social and Cultural Rights,[2] the Convention on the Elimination of All Forms of Discrimination against Women,[3] the Convention on the Rights of the Child[4] and the Convention on the Rights of Persons with Disabilities,[5]

Reaffirming its resolution 70/1 of 25 September 2015, entitled "Transforming our world: the 2030 Agenda for Sustainable Development", in which it adopted a wide, far-reaching and people-centred set of universal and transformative Sustainable Development Goals and targets, and its commitment to working tirelessly for the full implementation of the Agenda by 2030, with the endeavour to reach the furthest behind first, including persons living with a rare disease,

Recalling its resolutions 76/132 of 16 December 2021 and 78/173 of 19 December 2023,

Recalling also its resolutions 76/154 of 16 December 2021, 77/189 of 15 December 2022 and 79/149 of 17 December 2024, as well as previous relevant resolutions, and relevant resolutions of the Human Rights Council and of the Economic and Social Council and its functional commissions,

[1] Resolution 217 A (III).
[2] See resolution 2200 A (XXI), annex.
[3] United Nations, *Treaty Series*, vol. 1249, No. 20378.
[4] Ibid., vol. 1577, No. 27531.
[5] Ibid., vol. 2515, No. 44910.

Taking note of World Health Assembly resolution 78.11 of 27 May 2025, entitled "Rare diseases: a global health priority for equity and inclusion",[6] which, inter alia, mandates the development of a comprehensive 10-year draft global action plan for rare diseases, to be submitted for consideration by the World Health Assembly at its eighty-first session, in 2028,

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,

Reaffirming the right of every human being, without distinction of any kind, to the enjoyment of the highest attainable standard of physical and mental health and to a standard of living adequate for the health and well-being of oneself and one's family, including adequate food, safe drinking water, sanitation, clothing and housing, and to the continuous improvement of living conditions, with particular attention to the alarming situation of millions of people for whom access to healthcare services and medicines remains a distant goal, owing to a number of different barriers, such as inequitable access, high prices and financial hardship, in particular people who are in vulnerable situations, including those in developing countries,

Recognizing that some persons living with a rare disease have disabilities and impairments, which may have a greater impact on their health, and that they may also face attitudinal and environmental barriers, which may hinder their full and effective participation in society on an equal basis with others,

Reaffirming that health is a precondition for and an outcome and indicator of the social, economic and environmental dimensions of sustainable development and the implementation of the 2030 Agenda for Sustainable Development, and acknowledging the reciprocal benefits between the attainment of Sustainable Development Goal 3 and the achievement of all other Goals,

Recognizing the fundamental importance of equity, social justice and social protection mechanisms as well as the elimination of the root causes of discrimination and stigma in healthcare settings to ensure universal and equitable access to quality health services without financial hardship for all people, particularly for those who are in vulnerable situations, including those living with a rare disease,

Recognizing also that persons living with a rare disease and their families should have access to social protection and assistance that enables them to contribute towards the full and equal enjoyment of their rights and to ensure a safe and supportive family environment,

Recalling the outcomes of the high-level meetings on universal health coverage, held in New York on 23 September 2019 and 21 September 2023, and reaffirming their political declarations, entitled "Universal health coverage: moving together to build a healthier world"[7] and "Universal health coverage: expanding our ambition for health and well-being in a post-COVID world",[8] including the commitment therein to strengthen efforts to address rare diseases as part of universal health coverage,

Deeply concerned that pandemics and other public health emergencies perpetuate and exacerbate existing inequalities, and that those disproportionately at risk are women and girls and persons in vulnerable situations, and recognizing the multifaceted effects of pandemics, including the impact on access to essential health

[6] See World Health Organization, document WHA78.11.
[7] See resolution 74/2.
[8] Resolution 78/4, annex.

services and, in particular, on the health, social and economic situation of persons living with a rare disease,

Concerned that reaching the correct diagnosis can take over five years, that many persons living with a rare disease never receive an adequate diagnosis, and that insufficient screening programmes, including newborn screening, and unequal access to diagnostic services, infrastructure and expertise contribute to delayed diagnosis, when nearly half of genetic diseases start in childhood,

Recognizing that timely diagnosis and early access to health services can slow disease progression, save lives, and provide greater visibility and facilitate full inclusion on an equal basis with others for persons living with a rare disease,

Recalling the commitment to scale up efforts and further implement the political declaration of the high-level meeting on universal health coverage held in 2023 and to achieve the health-related Sustainable Development Goals and targets through, inter alia, strengthening national efforts, international cooperation and global solidarity at the highest political level,

Expressing concern that persons living with a rare disease and their families can be at greater risk of being disproportionately affected by stigma, discrimination and social exclusion, and that one of the major barriers to improving the inclusion and participation of persons living with a rare disease and their families in society is the lack of knowledge and expertise in the field and a lack of awareness regarding the issue,

Underscoring the need to address the root causes of inequality and discrimination faced by persons living with a rare disease and their families, and in this regard recognizing that there is a need for policies and programmes to prevent and combat prejudice, to foster inclusion and to create an environment conducive to respect for their rights and dignity,

Recognizing that persons living with a rare disease, including those whose disease is undiagnosed, and their families may be psychologically, socially and economically vulnerable throughout their life course, facing specific challenges in several areas, including but not limited to physical and mental health, education, employment, financial health and leisure,

Reaffirming that inclusive and equitable quality education and lifelong learning opportunities without discrimination are essential for the full, equal and meaningful participation in all aspects of social, cultural, political and economic life, and recognizing that, in particular, children living with a rare disease may face multiple challenges in accessing quality education owing to the inaccessibility of facilities and non-adapted teaching methods, among others,

Reaffirming also that access to full and productive employment and decent work is also an important aspect of full, equal and meaningful participation in society and economic life, and that persons living with a rare disease and their families face challenges in access to, retention of and return to employment,

Reaffirming further the need to achieve gender equality and to empower women and girls, and concerned by the fact that women and girls living with a rare disease face more discrimination and barriers in accessing healthcare services, including sexual and reproductive healthcare services, and education, as well as fully, equally and meaningfully participating in public life, and that women and girls undertake a disproportionate share of unpaid care and domestic work when a member of their household or family lives with a rare disease, and that women face more barriers in accessing decent work,

Deeply concerned that persons living with a rare disease, especially women and children, often face barriers in accessing water and sanitation facilities that are accessible and appropriate to their needs, which has an impact on their ability to participate fully in all aspects of life, including their access to education, and for women to live independently and ensure their access to employment, which is particularly concerning in situations of homelessness,

Recognizing the need to foster innovation and the positive contribution that innovation can make in promoting social cohesion, reducing inequalities and expanding opportunities for all, including persons living with a rare disease and people in the most vulnerable situations, and in that regard recognizing the need to support, streamline and increase attention to research on rare diseases,

Expressing concern at the lack of disaggregated data, including by income, sex, age, race, ethnicity, migration status, disability, geographical location and other characteristics relevant in national contexts, on persons living with a rare disease, which would help to identify and address the barriers faced in exercising their human rights,

Recognizing the important role that civil society organizations and academic institutions play in collecting, analysing and disseminating the limited existing information on the challenges of persons living with a rare disease and in providing support services to them and advocating on their behalf for better lives,

Recognizing also the need for the participation of persons living with a rare disease in civil, political, social, economic and cultural life, and that the effective and meaningful participation of persons living with a rare disease in decision-making, including through their representative organizations, can strengthen the effectiveness of national, regional and international policy and development programmes related to persons living with a rare disease,

1. *Calls upon* Member States to strengthen health systems and referral systems between primary health care and other levels of care, in order to provide universal access to a wide range of healthcare services that are safe, of quality, accessible, available and affordable, timely, clinically and financially integrated, and gender-responsive, with full respect for human rights, which will help to empower persons living with a rare disease, whether genetic or acquired, including those with rare infections and rare allergic conditions, as well as those with an undiagnosed rare disease, in addressing their physical and mental health needs to realize their human rights, including their right to the highest attainable standard of physical and mental health, to enhance health equity and equality, end discrimination and stigma, eliminate gaps in coverage and create a more inclusive society;

2. *Encourages* Member States to adopt gender-sensitive national strategies, action plans and legislation to contribute to the well-being of persons living with a rare disease and their families, including on the protection and enjoyment of their human rights, consistent with their obligations under international law;

3. *Also 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;

4. *Emphasizes* the important role of cultural, family, ethical and religious factors, including the key role played by religious leaders in the treatment, care and support of persons living with a rare disease;

5. *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;

6. *Encourages* Member States to foster the creation of networks of experts and multidisciplinary specialized expert hubs, inter alia, for rare diseases, to promote correct and timely diagnoses and care coordination plans, and to increase support for research, by strengthening international collaboration and coordination of research efforts and the generation and sharing of data, while respecting data protection and privacy;

7. *Also encourages* Member States:

(a) To develop national sustainable programmes for undiagnosed diseases, aligned with national efforts to achieve universal health coverage, to enable rapid and equitable access to diagnosis and social support;

(b) To structure and coordinate, at the national and international levels, knowledge on the subject of rare diseases, and information-sharing to optimize the use of existing resources and facilitate access for all persons with an undiagnosed rare disease, while acknowledging the need to support developing countries in building expertise and in developing local and regional manufacturing capacities for health products and technologies;

(c) To promote the participation of persons living with a rare disease and other relevant stakeholders in the governance of undiagnosed disease programmes and international networks to adequately address the priorities of persons living with an undiagnosed rare disease and contribute to improving the quality of healthcare;

(d) To promote, through existing initiatives, ethical and responsible international data-sharing to support diagnosis in accordance with applicable national data protection legislation, increase clinical collaboration, facilitate research and accelerate treatment of undiagnosed and rare conditions;

(e) To facilitate collaboration among national authorities overseeing drug development cycles and clinical trials for treatments for persons living with a rare disease;

(f) To develop and implement, where appropriate, national mechanisms, which might include surveys, patient registries and participatory questionnaires, in consultation with persons living with a rare disease and their representative organizations, to systematically assess the medical, social and economic challenges faced by these persons and their families, in order to inform national policies, improve service delivery and guide the design of equitable health and social protection programmes, while ensuring full respect for privacy and data protection standards;

8. *Urges* Member States to implement, as appropriate, national policies and measures to ensure that persons living with a rare disease are not left behind, recognizing that persons living with a rare disease are often disproportionally affected by poverty, discrimination and a lack of education, decent work and employment, and that they may require assistance in order to enjoy equal access to benefits and services, notably in the fields of education, employment and health, and to promote their full, equal and meaningful participation in society, and to commit to working towards the social integration and physical and mental well-being of persons living with a rare disease and their families and caregivers without any discrimination;

9. *Urges* Member States, United Nations agencies and other stakeholders, in consultation with persons living with a rare disease and their families and caregivers,

including through their representative organizations, to design and implement policies and programmes, to share experiences and best practices with the aim of fulfilling the rights of all persons living with a rare disease, and to ensure that the implementation of the 2030 Agenda for Sustainable Development[9] is inclusive of and accessible to persons living with a rare disease;

10. *Affirms* that all persons, including those living with a rare disease, and especially children, have the right to education and lifelong learning opportunities on the basis of equal opportunity and non-discrimination, and urges Member States to ensure full and equal access to education and lifelong learning opportunities for persons living with a rare disease on an equal basis with others;

11. *Invites* Member States, in line with national policies, to include rare disease content in the education and training of medical students, nurses and other health practitioners, including in continuing professional development, in order to strengthen knowledge, improve early detection and care pathways and promote respectful, dignified and inclusive care for persons living with a rare disease, as well as collaboration with them and their families;

12. *Urges* Member States to implement effective programmes to promote mental health and psychosocial support for persons living with a rare disease, and to promote policies and programmes that enhance the well-being of their families and caregivers;

13. *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, as well as those with an undiagnosed 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, and those with an undiagnosed rare disease, with quality essential health products, health services, including adequate preventive measures such as newborn screening, and quality, safe, effective, affordable and essential medicines and therapies, diagnostics, with the particular aim of shortening and easing the pathway to a diagnosis and treatment for persons living with a rare disease, health technologies, and strengthened primary healthcare, referral pathways, multidisciplinary care coordination plans, increased registration efforts, and access to specialized care, with a view to completely covering all persons living with a rare disease by 2030;

(b) To reverse the trend of catastrophic out-of-pocket health expenditure, which carries psychosocial and economic consequences for both persons living with a rare disease and their families, 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;

14. *Encourages* Member States to take appropriate steps to provide affordable, accessible and good-quality care facilities for children and other dependants living with a rare disease and measures promoting the equal sharing of household responsibilities between women and men, including all adult members of the household, recognizing, reducing and redistributing women's and girls' disproportionate share of unpaid care and domestic work when a member of the family lives with a rare disease, and fully engaging men and boys as agents and beneficiaries of change and as strategic partners and allies in this regard;

[9] Resolution 70/1.

15. *Also encourages* Member States to promote access to full and productive employment and decent work, along with appropriate measures for financial inclusion for persons living with a rare disease and their families by addressing challenges in access to, retention of and return to employment, inter alia, through the creation of suitable working conditions for persons living with a rare disease and their families, expanding flexible working arrangements, including through the use of new information and communications technologies, and providing and/or expanding leave arrangements, such as sick leave and caregiver's leave, and adequate social security benefits for both women and men, taking appropriate steps to ensure that they are not discriminated against when availing themselves of such benefits;

16. *Further encourages* Member States to eliminate barriers faced by persons living with a rare disease and their families in accessing water, sanitation and hygiene, including physical, institutional, social and attitudinal barriers, and to promote appropriate measures in cities and other human settlements that facilitate such access for persons living with a rare disease and their families, on an equal basis with others, in both rural and urban areas;

17. *Invites* Member States, in collaboration with non-governmental organizations, civil society organizations and other relevant stakeholders, to raise awareness of the specific challenges and needs faced by persons living with a rare disease and their families, through national campaigns, educational programmes and information dissemination, with the goal of promoting greater understanding and global solidarity;

18. *Requests* the Secretary-General, in close collaboration with the Director General of the World Health Organization, to report on and assess the implementation of the present resolution to the General Assembly at its eighty-second session, through an oral update, to be followed by an interactive dialogue;

19. *Invites* Member States to continue to consider, at future sessions of the General Assembly, addressing the multidimensional challenges faced by persons living with a rare disease, including with respect to access to quality, safe, effective and affordable diagnostics and therapies, as well as the challenges faced by their families and caregivers, while identifying possible implementation gaps in the protection of the human rights of persons living with a rare disease, including options for the elaboration of an agreement, guidelines, an international convention or other international standards;

20. *Decides*, given the multifaceted nature of the challenges faced by persons living with a rare disease, to continue its consideration of the issue of persons living with a rare disease at its eighty-second session, under the item entitled "Social development".

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