

WHAT IS
EQUITY

FOR PEOPLE LIVING
WITH A RARE DISEASE?



RARE DISEASE DAY®

HOW CAN WE ACHIEVE EQUITY FOR PEOPLE WITH RARE DISEASES?

WHAT DOES EQUITY MEAN FOR PEOPLE LIVING WITH A RARE DISEASE?

Equity in practice means recognising and meeting people's specific needs while eliminating barriers preventing their full participation in society. It contrasts with equality which promotes fairness by treating everyone equally, regardless of their needs.

For people with rare diseases, **equity means having social opportunities, non-discrimination in education and work, and fair access to health, social care, diagnosis and treatment.**

On Rare Disease Day, we call for action to ensure people living with a rare disease have the **same opportunities to fully participate in family life, work, and social activities.** Our long-term goal is to achieve this over the next decade.

THE CHALLENGE

The 300 million people with a rare disease globally and their families face common challenges. As a vulnerable and often neglected population, they are disproportionately affected by stigma, discrimination and social marginalisation, both within their social environment and in society at large.

“Equity recognises that each person has different circumstances and allocates the exact resources and opportunities needed to reach an equal outcome.”

Sarah, Australia

“Equity for people with rare diseases means recognising that we do not all start from the same place and that we must acknowledge and make adjustments to imbalances.”

Ulrike, Austria

“Equity means inclusion and support so that my child can reach her full potential, despite the challenges she faces.”

Marta, Portugal

HOW CAN WE ACHIEVE EQUITY FOR PEOPLE WITH RARE DISEASES?

EQUALITY VS EQUITY

Equality involves treating everyone the same, often by providing identical resources or opportunities to all individuals, regardless of their unique circumstances. This approach assumes that everyone starts from a similar position, which isn't always the case.

Equity, on the other hand, recognises that people have different needs and challenges and therefore requires distributing resources and opportunities based on individual circumstances to create fair outcomes.

Equity addresses existing disparities by providing tailored support, aiming to bring everyone to a similar level of opportunity or success.

In essence, while equality promotes uniform treatment, equity focuses on fairness by recognising and addressing inequalities.



HOW CAN WE ACHIEVE EQUITY FOR PEOPLE WITH RARE DISEASES?

RARE DISEASES

- Affect 3.5% to 5.9% of the population during their lifetimes.
- 72% of rare diseases are genetic.
- 70% of genetic rare diseases begin in childhood.
- No cure exists for most of these diseases, and there are few treatments available.

There are over 6,000 rare diseases, many of which are chronic, progressive, degenerative, disabling, and often life-threatening. Due to the rarity of each disease and scattered populations, expertise and information are scarce. In health and support systems designed for common diseases, those with a rare disease face inequities in accessing diagnosis, care and treatments.

People with rare diseases also face discrimination at work, school and leisure activities.

For instance, a EURORDIS Rare Barometer survey on '[Juggling care and daily life: The balancing act of the rare disease community](#)' found that 94% of respondents who had difficulties accessing higher education reported that their disease limited their professional choices.

“Social inclusion means providing adaptations in public spaces, schools, and workspaces to facilitate daily activities for people with disabilities. It is about respect, inclusion, and support.”

Daniela, Mexico

“Equity is the ability to get an early and correct diagnosis from an expert in the relevant field of medicine. Equity means having access to a high level of treatment no matter which country you live in.

“Equity is being able to be treated at an expert centre where a multidisciplinary team is available. Equity means having medical professionals who care about the quality of life of patients!”

Lidiya, Bulgaria

HOW CAN WE ACHIEVE EQUITY FOR PEOPLE WITH RARE DISEASES?

KEY MILESTONES

- 1983: The United States passed the Orphan Drug Act
- 1999: The EU adopted the Regulation on Orphan Medicinal Products
- 2008: First Rare Disease Day celebrated
- 2011: International Rare Diseases Research Consortium (IRDiRC) established
- 2014: NGO Committee for Rare Diseases created
- 2019: UN Political Declaration on Universal Health Coverage included rare diseases
- 2019: People with rare diseases recognised in the OHCHR Report on UHC and Human Rights as a key focus group for implementing UHC within the human rights framework.
- 2021: UN Resolution on "Addressing the Challenges of Persons Living with a Rare Disease" adopted
- 2023: UN Resolution renewed, now including people with undiagnosed diseases.
- 2024: Rare diseases are included for the first time in the WHO Fourteenth General Programme of Work (GPW 14).

ADVOCATING FOR SOCIAL INCLUSION

People with rare diseases have the right to participate in society on an equal basis with others. To do so, they must be provided with comprehensive care and support which address their health, social and daily needs.

The UN's 2030 Agenda and Sustainable Development Goals provide a strategic framework, focusing on key areas like education, gender equality, and reducing inequality. Protecting the rights of people with rare diseases is crucial to fulfilling the UN's commitment to leave no one behind.

“At school, it means providing tailored educational resources and support, such as access to medical care on campus and educational accommodations, to ensure they have the same opportunities for success as their peers.”

Ajith, Sri Lanka

HOW CAN WE ACHIEVE EQUITY FOR PEOPLE WITH RARE DISEASES?

TAKE ACTION

Start a conversation: Talk to people in your community to spread awareness about rare diseases. [Share your story](#) or the [stories of those who inspire you](#). The more voices that join, the stronger our demand for equity becomes.

Explore events and activities: Discover [events happening globally](#). Join patient organisations and communities, or even [create your own event](#) to raise awareness or donations.

Download campaign materials: [Access a range of materials](#) including social media graphics, videos, posters, badges, banners, and toolkits to help raise awareness in your own unique way.



READ A STORY



FIND AN EVENT



POST A STORY



ALL RESOURCES

Contact policymakers: Write a letter to a decision-maker highlighting the needs of people with rare diseases and invite them to a Rare Disease Day event that focuses on a key policy issue. Share this fact sheet and encourage their involvement in supporting change.

Get media and celebrity attention: Leverage media attention on Rare Disease Day to launch a new initiative for the rare disease community. Enlist celebrities to support the cause by encouraging them to share a #RareDiseaseDay post on social media and raise awareness.

“In the workplace, equity means offering accommodations and support, like flexible schedules or remote work options, to ensure they can perform their jobs effectively.”

Ajith, Sri Lanka

“At work, I have a mirror to help with peripheral vision.”

Marta, Portugal

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LITERATURE

NGO Committee for Rare Diseases, EURORDIS, RDI, FEDER. [Joint Statement on UHC at the United Nations](#) (2023)



EURORDIS-Rare Diseases Europe. [Championing the Rare: Building the Engine of an Inclusive European Health Union](#) (2023)



UNGA, [Resolution on Addressing the Challenges of Persons Living with a Rare Disease and their Families](#), A/RES/76/132 (2021)



Nguengang Wakap, S., Lambert, D.M., Olry, A. et al. [Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database](#). Eur J Hum Genet 28, 165–173 (2020).



Rare Diseases International. [Rare Diseases: Leaving No One Behind in Universal Health Coverage](#) (2019).



Statement: [Health Equity The perspective of Persons Living with a Rare Disease \(PLWRD\)](#), 2021



You can also visit the [Rare Diseases International website](#) and the [EURORDIS-Rare Diseases Europe resource page](#) to access position papers, survey results, reports, and other materials on a variety of topics, including diagnosis, treatments, holistic care, mental health and well-being, data, digital health, and more.



**MORE
THAN YOU CAN
IMAGINE**

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