

# EQUITY FOR PEOPLE LIVING WITH A RARE DISEASE



## EQUITY FOR PEOPLE LIVING WITH A RARE DISEASE

is equitable access to **diagnosis, treatment, health, social care and opportunity**

### What equity means for people living with a rare disease?

Equity in practice means meeting people's specific needs and eliminating barriers preventing their full participation in society. For people living with a rare disease equity means social opportunity, equitable access to health and social care, diagnosis and treatment.

**On Rare Disease Day we call for action for people living with a rare disease to have equal opportunities to realise their potential for participation in family, work and social life.**

**The long-term goal of Rare Disease Day over the next decade is increased equity for people living with a rare disease and their families.**

### The challenge

The **300 million people** living with a rare disease around the world and their families face common challenges in their daily lives. As a vulnerable and neglected population they face social isolation.

There are over **6000 rare diseases** that are chronic, progressive, degenerative, disabling and frequently life threatening. Due to the rarity of each individual disease and scattered populations, expertise and information is scarce. In health systems designed for common diseases patients face inequities in accessing diagnosis, care and treatments.

People living with a rare disease also face discrimination at work and school. In a EURORDIS [Rare Barometer survey on 'Juggling care and daily life: The balancing act of the rare disease community'](#) 94% of the respondents who reported difficulties in accessing higher education declared that the disease has limited their professional choices.

#### Key statistics on rare diseases

- Over **300 million people** around the world are living with a rare disease.
- There are **over 6,000** identified rare diseases.
- **72%** of rare diseases are genetic
- **70%** of genetic rare diseases start in childhood.

Research recently published in the European Journal of Human Genetics, article authored by EURORDIS-Rare Diseases Europe, Orphanet & Orphanet [Ireland "Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database"](#).

## How can we achieve equity for people living with a rare disease?

### 1. Advocating for the social inclusion of people living with a rare disease

In order to achieve equitable social inclusion for people living with a rare disease, they must first have access to holistic care covering the 360° spectrum of health, social and everyday needs as argued in a [EURORDIS position paper on Achieving Holistic Person-Centred Care to Leave No One Behind](#).

The [UN 2030 Agenda and its Sustainable Development Goals](#) provide an important framework for addressing the full spectrum needs of people living with a rare disease. The Goals target issues beyond health, including education, gender, work and inequality.

Global institutions protecting human rights seek to address the health care challenges of people living with a rare disease. The [Human Rights Council Resolution on access to medicines and vaccines](#) recognises the importance of development, access and affordability of treatments for rare diseases.

The following legislation promotes social inclusion for people with a disability, including those whose disability is a result of living with a rare disease: The [UN Convention on the Rights of People with Disabilities \(CRPD\)](#) and the [report of the Special Rapporteur on the rights of persons with disabilities to 73<sup>rd</sup> Session of the UNGA](#).

### 2. Including rare diseases in universal health coverage to leave no one behind

Addressing the needs of people living with a rare disease is central to achieving the UN 2030 Agenda and its Sustainable Development Goals and its pledge to leave no one behind.

To achieve this, we should move towards a strategy for universal health coverage (UHC) that addresses the needs of those living with a rare disease.

The [United Nations Office of the High Commissioner for Human Rights \(OHCHR\)](#) stressed the need to address rare diseases within UHC in the annual report to the UN Economic and Social Council (ECOSOC).

A hugely significant milestone has been reached with [the inclusion of rare diseases in the political declaration on UHC](#) adopted by all UN Member States, thanks to the advocacy efforts of the rare disease community, led by EURORDIS, Rare Diseases International and the NGO Committee for Rare Diseases.



The long-term goal is a  
United Nations General Assembly  
Resolution on rare diseases.

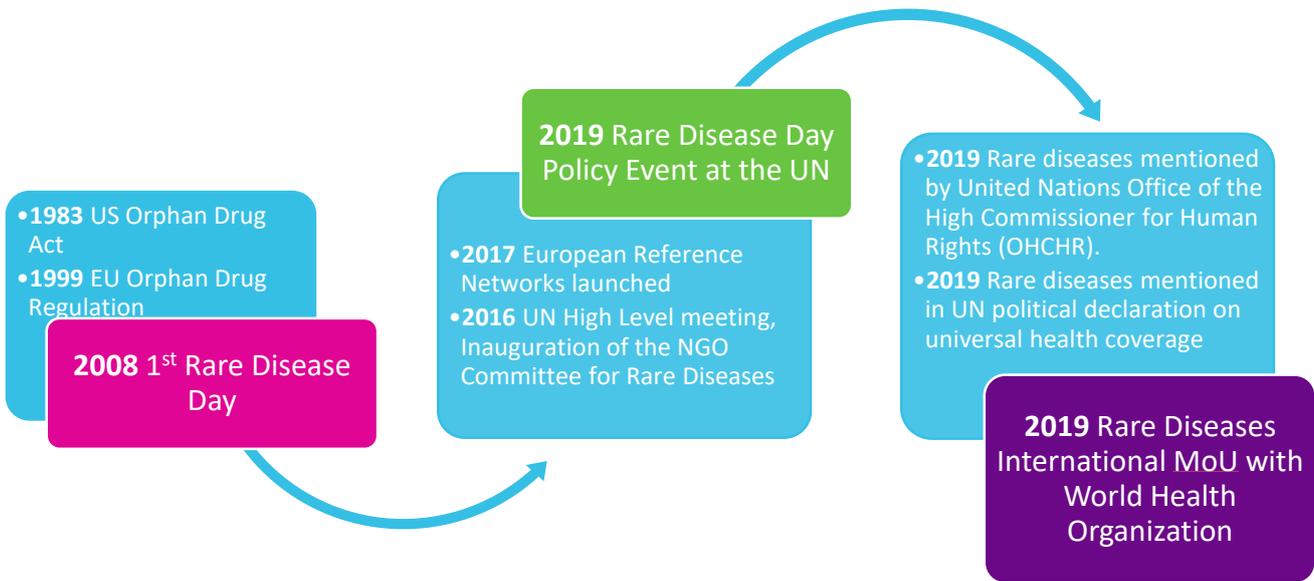


Yann Le Cam, Chief Executive Officer EURORDIS-Rare Diseases Europe, Dr Tedros, Director-General of the World Health Organization (WHO), Durhane Wong Rieger, Chair of the Council of RDI. World Health Organization, Geneva, March 2019.

**“WHO’s top priority is to support countries on the path towards universal health coverage [...] This includes access to diagnosis and treatment for people who suffer from rare diseases”**

Dr. Tedros Adhanom Ghebreyesus,  
WHO, 28 February 2018

## Milestones in achieving equity



## Actions you can take on Rare Disease Day to advocate for equity

- ✓ Write a letter to a key decision-maker in your community to highlight the importance of addressing the needs of people with a rare disease and share this fact sheet with them.
- ✓ Invite a decision-maker to attend your Rare Disease Day event.
- ✓ Hold a Rare Disease Day event that highlights a key local or national policy issue for the rare disease community.
- ✓ Use media attention on Rare Disease Day to launch a new initiative for the rare disease community.

## Key resources and information

### About rare diseases

Use of statistic '300 million people globally living with a rare disease'.

- [Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database, European Journal of Human Genetics, by EURORDIS-Rare Diseases Europe, Orphanet & Orphanet Ireland.](#)
- [EURORDIS press release: New scientific paper confirms 300 million people living with a rare disease worldwide](#)
- [What is a rare disease webpage \(on rarediseaseday.org\)](#)
- [Rare Disease Day 2020 Infographics](#)
- [Dr Tedros tweet 28.02.19](#)
- [Opening Remarks by H.E. Mr. Sven Jürgenson, Permanent Representative of Estonia at the Rare Disease Day Policy Event, New York, 21 February 2019](#)

### The impact of rare diseases on daily life

- [EURORDIS position paper: Achieving Holistic Person-Centred Care to Leave No One Behind](#)
- [Rare Barometer survey report on 'Juggling care and daily life: The balancing act of the rare disease community'](#)
- [Rare Barometer survey infographic on 'Juggling care and daily life: The balancing act of the rare disease community'](#)
- [Disability and rare disease: towards person-centred care for Australians with rare diseases, The McKell Institute](#)

### Human rights of people living with a rare disease

- [Human Rights Council Resolution on access to medicines and vaccines](#)
- [UN Convention on the Rights of People with Disabilities](#)
- [Report of the Special Rapporteur on the rights of persons with disabilities to 73rd Session of the UNGA.](#)

### Rare diseases in the Sustainable Development Goals and universal health coverage

- [Rare Diseases International position paper: Universal health coverage](#)
- [Universal Health Coverage campaign toolkit](#)
- [News article, RDI: United Nations human rights body stresses the need to address rare diseases within Universal Health Coverage](#)
- [EURORDIS press release: UN Member States include rare diseases in political declaration on universal health coverage](#)
- [NGO Committee for rare diseases press release: Rare Disease Day 2019 Policy Event at the United Nations](#)
- [NGO Committee for rare diseases event report: Rare Disease Day 2019 Policy Event at the United Nations](#)
- [NGO Committee for rare diseases event report: The Right to Health: The Rare Disease Perspective, Rare Diseases International Policy Event 2017](#)
- [NGO Committee for rare diseases event report: Global Gathering for Rare Diseases: Inauguration of the NGO Committee for Rare Diseases 2016](#)

***Rare Disease Day is organised by EURORDIS-Rare Diseases Europe and 60 national alliances of rare disease patient organisation partners.***

