

EQUITY

FOR PEOPLE LIVING WITH A RARE DISEASE

WHAT DOES EQUITY MEAN 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, non-discrimination in education and work, and equitable access to health, 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 **full 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 are disproportionately affected by stigma, discrimination and social marginalization, within their social environment as well as society at large.

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 and support systems designed for common diseases people living with a rare disease face inequities in accessing diagnosis, care and treatments.

People living with a rare disease also **face discrimination at work, school and leisure**. For instance 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 OF RARE DISEASES



Affects between **3.5 and 5.9%** OF THE POPULATION in the course of their lives.



72 % OF RARE DISEASES ARE GENETIC.



70 % OF GENETIC RARE DISEASES START IN CHILDHOOD



NO CURE for the majority of diseases and few treatments available.

HOW CAN WE ACHIEVE EQUITY FOR PEOPLE LIVING WITH A RARE DISEASE?



1

ADVOCATING FOR SOCIAL INCLUSION FOR 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 \(SDGs\)](#) provide an important framework for addressing the full spectrum of needs of people living with a rare disease. The Goals target important issues including education, gender, work and inequality. **Addressing the needs of people living with a rare disease is central to achieving the UN 2030 Agenda**, the SDGs and its pledge to leave no one behind. 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 \(CRPD\)](#) encourages governments to develop and implement policies and practices targeting the most marginalized groups of persons with disabilities such as those living with a rare disease.

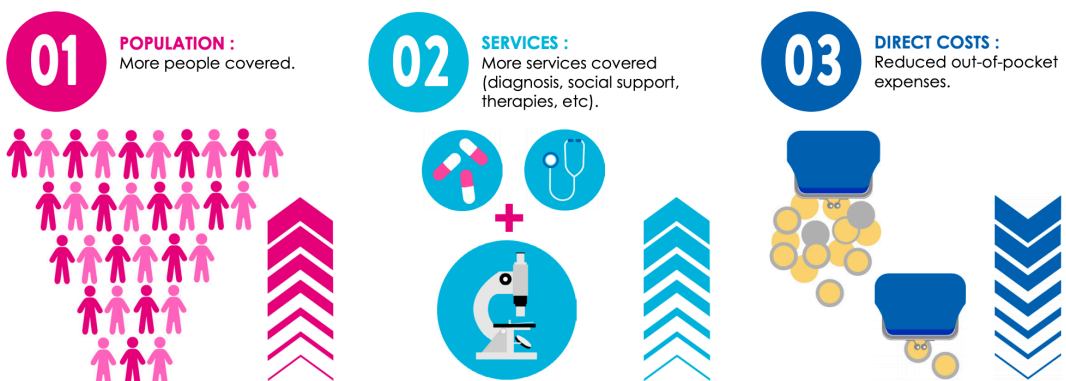
2

INCLUDING RARE DISEASES IN UNIVERSAL HEALTH COVERAGE TO LEAVE NO ONE BEHIND

Universal Health Coverage (UHC) is a safeguard of equity and people living with a rare disease need to be included in national strategies for UHC and essential health service packages. **UHC ensures all people, everywhere, can access the quality essential health services they need without being exposed to financial hardship.** UHC includes three dimensions of coverage: in terms of population, services and proportion of costs covered.

UHC is firmly rooted in the right to health and requires strong political leadership. In September 2019 all 193 UN Member States adopted the Political Declaration on UHC, which includes the need to strengthen efforts to address rare diseases. While countries around the world are at different stages in the development of policies in support of the rare disease community, **any country can today take decisive action to support a greater integration of rare diseases in its UHC model** or approach. It is possible to make great progress at a rapid pace even if starting from very little.

Governments can focus on 1) extending coverage to people living with a rare diseases by promoting visibility, codification and diagnosis; 2) Including other services and adapting existing ones to the needs of the rare disease population; and 3) Protecting the rare disease population from further financial hardship.



RARE IS **MANY** RARE IS **STRONG** RARE IS **PROUD**



RAREDISEASEDAY.ORG

A UNITED NATIONS GENERAL ASSEMBLY RESOLUTION ON PERSONS LIVING WITH A RARE DISEASE

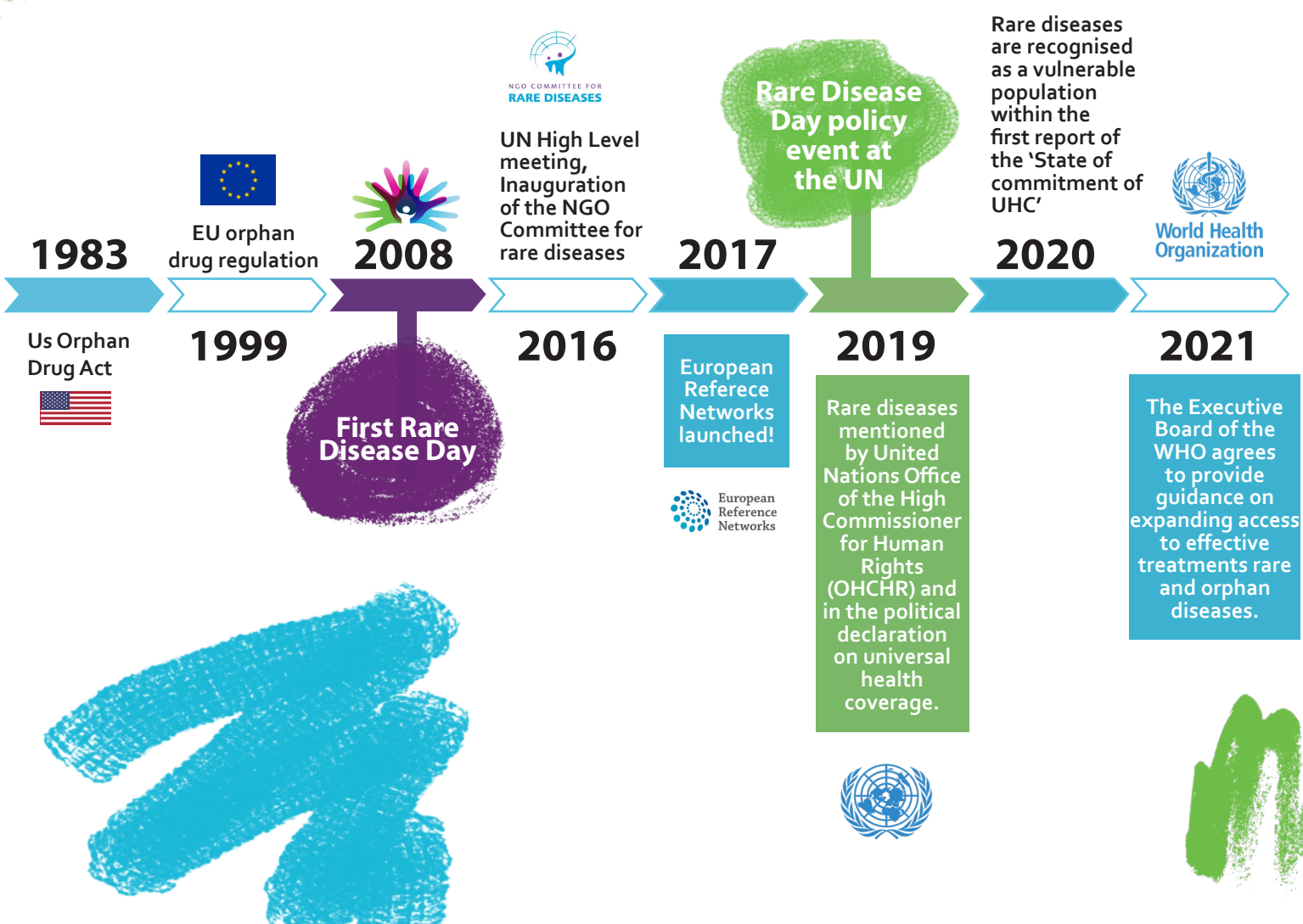
To ensure equity for people living with a rare disease, it is necessary for countries to collectively **promote measures that are multidisciplinary, holistic and person-centred**, and that ensure non-discrimination and opportunities to contribute to society.

To ensure these whole-of-society measures, the rare disease community, represented by the NGO Committee for Rare Diseases, Rare Diseases International and EURORDIS, are calling on UN Member States to **adopt a United Nations General Assembly Resolution on persons living with a rare disease and their families**.

A UNGA Resolution would promote global collaboration, national strategies and policies, as well as the inclusion of people living with a rare disease in the work of the United Nations and its agencies and bodies.

LEAVE NO ONE BEHIND!

MILESTONES IN ACHIEVING EQUITY



HOW CAN I ADVOCATE FOR EQUITY?



- 1 Write a **LETTER TO A KEY POLICY-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.
- 2 Hold a **RARE DISEASE DAY ONLINE EVENT** that highlights a key local or national policy issue for the rare disease community and invite a decision-maker to attend.
- 3 Use **MEDIA ATTENTION** on Rare Disease Day to launch a new initiative for the rare disease community.

KEY RESOURCES AND INFORMATION

ABOUT RARE DISEASES

- [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](#)
- [Rare Barometer survey on rare disease patients' experience of COVID-19](#)

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](#)
- [State of UHC implementation report](#)
- [UHC for Rare Diseases Campaign](#)
- [Development of the roadmap on access to medicines and vaccines 2019-2023](#)
- [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](#)