

UN High Level Meeting on Universal Health Coverage (UHC)

23rd September 2019

Statement on behalf of the rare disease community

The rare disease community strongly supports the UN Political Declaration on UHC and welcomes the opportunity to make a joint statement at this High Level Meeting represented by Rare Diseases International and EURORDIS-Rare Diseases Europe.

Each rare disease affects a small number of patients in each country but, when considered all together, the 6000+ rare diseases are affecting a minimum of 4% of the population in each country and 300 million people worldwide.

Rare diseases are genetic disorders, rare bacterial or viral infections, rare poisonings and rare cancers. In 70% of cases, rare genetic disorders appear during childhood. Rare diseases are chronic, complex, progressive, disabling, and life-threatening.

Many people affected live in the margins of society, often undiagnosed, unrecognized, and unable to access services available to common conditions. These factors have a huge impact on family finances and mental health, and are detrimental to their active participation in society. As such, people living with a rare disease constitute a vulnerable and neglected population, mostly invisible to the system regardless of their own socio-economic circumstances, and of the level of development of the country.

However, the rare disease community has developed strategies and solutions which can translate into better inclusion in society, better health outcomes and survival (even within existing resources), and the reduction of social and economic inequities.

The inclusion of rare diseases within UHC, taking a human rights approach, will be an opportunity to scale up these strategies and ensure that truly no one is left behind.