



## *NORD/ EURORDIS-Rare Diseases Europe Joint Statement on COVID-19 and Orphan Drug Legislation*

### **US and European rare disease patient alliances, the National Organization for Rare Disorders (NORD®) and EURORDIS-Rare Diseases Europe call for the expeditious development of COVID-19 treatments without the use of orphan drug incentives**

The National Organization for Rare Disorders (NORD) and EURORDIS-Rare Diseases Europe share the global concern that diagnostics, therapeutics and vaccines to address COVID-19 be developed expeditiously. Our organizations represent the 30 million people in the US and 30 million people in the EU living with rare diseases. These individuals are disproportionately at risk if they contract this disease and will be among those who benefit the most when such products are developed and made available.

Notwithstanding our community's stake in solutions for COVID-19, we do not believe that rare disease incentives that exist under our respective laws, the Orphan Drug Act in the US and the EU Regulation on Orphan Medicinal Products, are appropriate for use in this global pandemic in which hundreds of thousands, if not millions, will be affected. These laws have been highly successful at spurring development of therapeutics for those rare diseases which affect a very small number of people in the population and where there was a lack of investment in research. That is an entirely different problem than the current one.

Clearly, there exists a viable market of people infected by SARS CoV-2 or patients affected by COVID-19 in our respective territories, and our regulatory bodies have sufficient and flexible authorities at their disposal to facilitate the expeditious review of these products. There is no need for rare disease incentives to spur investment.

We emphasize the importance of global and open collaboration on research for treatments and vaccines, as pooling knowledge and resources is the best way to expedite availability of these medicines.

#### **About the National Organization for Rare Disorders (NORD)**

[The National Organization for Rare Disorders](#) (NORD) is the leading independent advocacy organization representing the over 25 million Americans affected by rare diseases. NORD is committed to the identification, treatment and cure of more than 7,000 rare diseases, of which approximately 90% are still without an FDA-approved treatment or therapy. NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. For more than 35 years, NORD has led the way in voicing the needs of the rare disease community, driving supportive policies and education, advancing medical research and providing patient and family services for those who need them most. Today NORD is home to over 300 member organizations and nearly 15,000 advocates.

#### **About EURORDIS-Rare Diseases Europe**

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 900 rare disease patient organisations from 72 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.