

EURORDIS Communiqué

## EURORDIS-Rare Diseases Europe addresses the concerns of its members on the supply of COVID-19 vaccines and other medicinal products

EURORDIS addressed the concerns of rare disease patient organisations funding therapy development and engaged in the clinical development of orphan medicines around current shortages of raw materials, which are slowing down the therapy development activities in Europe.

**11 June, Paris** – EURORDIS-Rare Diseases Europe, following an inquiry from member organisations on the availability of COVID-19 vaccines and other medicinal products, has contacted the cabinet of Mr. Thierry Breton, European Commissioner for the Internal Market, to explain shortages of raw materials, ingredients and consumables used in the manufacturing of gene therapy treatments.

On 26 May, EURORDIS met with the European Commission, which assured that the EU is set to bounce back from the current crisis by September 2021 when the demand in the United States will be met, allowing for a smoother delivery to other world regions.

The Commission has long been aware of the industrial challenges to beat the COVID-19 pandemic. Consequently, in February 2021 it created a Task Force, composed of Member States representatives, Commission officials (including DG SANTE) and industry (Task Force for industrial scale-up TFIS) to address supply chain bottlenecks affecting COVID-19 vaccine manufacturing and the production of other pharmaceutical products, including orphan medicines.

**EURORDIS will continue to inform the Task Force on products of special concern and liaise with the TFIS Task Force to ensure that vaccines and medicines are made available and people living with a rare disease can receive the treatment they require in the near future.**

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### EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of 962 rare disease patient organisations from 73 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. Follow @EURORDIS on Twitter or see the EURORDIS Facebook page. For more information, visit [eurordis.org](http://eurordis.org).

### Rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date, affecting an estimated 30 million people in Europe and 300 million worldwide. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.