

STATEMENT

by EUROPABIO on Rare Disease Day

More than 300 million people worldwide, and 30 million in Europe, live with a rare disease. On Rare Disease Day, EuropaBio and its members are very proud to be part of the solution for patients.

Europe has created a thriving research and innovation community to address the rarest of diseases, and changed the lives of adults and children worldwide. It has built upon this significant research foundation with SMEs focussed into rare diseases, bringing the skills and investment needed for development of therapies. In this context, Europe needs to continue to promote a stable regulatory environment to foster innovation in the area of rare diseases.

We need to fully empower this innovation engine and pipeline by unlocking more public and private funding for start ups and SMEs, enhancing the conditions for R&D productivity, and implementing coherent long term market access conditions for a competitive Europe.

EuropaBio makes the call:

- European Union, Member States, plus public and private stakeholders must work together towards accessible therapies for rare disease patients
- Foster rare disease ecosystems and translate cutting edge European research into solutions for unmet medical needs
- Boost investment into basic research, to deliver the scientific advances from which Europe fills its innovation pipeline, particularly in cell and gene therapies – delivering the science, infrastructure and skills that underpin next generation healthcare
- Enable and harness the full strength and industrial collaboration potential of European Reference Networks for maximum benefit to rare disease patients across Europe
- Ensure appropriate incentives that stimulate competition amongst innovators and reward risk, for commitment to rare disease pipelines in companies large and small

