



Statement

## European rare disease community welcomes the European Parliament's proposal for an ambitious EU4Health programme

16 October 2020, Paris – EURORDIS welcomes the European Parliament's €9.4 billion proposal for the EU4Health Programme, and now urges the German Presidency of the European Council to match this and to specifically recognise the place of rare diseases as a public health priority

EURORDIS-Rare Diseases Europe, representing 30 million people in Europe living with a rare diseases and their families, welcomes the position of the Environment and Public Health Committee at the European Parliament to restore the budget allocation for the EU4Health programme to the same level initially proposed by the European Commission.

**We now urge the Council to work together with the European Parliament towards a budget that truly protects European patients and citizens, leaving no one behind.**

The budget of €9.4 billion for the EU4Health Programme – which European member states proposed to drastically cut in July - will allow Europe's health systems to rise to the challenge posed by COVID-19, and continue to support the cross-border and EU wide initiatives that bring so much added value to people living with rare diseases.

We welcome in particular the strengthening and streamlining of funding for the European Reference Networks (ERNs) for rare and complex diseases. These are exemplar areas where integrated work among Member States has proven to have strong added value, with effective integration within national health systems through the revision of rare diseases plans, along with the strengthening of Centres of Expertise. The funding allocation proposed by the European Parliament for Orphanet, a unique resource gathering knowledge and accurate data on rare diseases across Europe, is warmly received. This is essential to improve the diagnosis, care and treatment of people living with rare diseases and instrumental for ERNs to perform their role.

**Yann Le Cam**, Chief Executive Officer, EURORDIS, commented:

"We asked the European Parliament back in July to stand up against cuts to the #EU4Health budget, and are delighted that they have come back with a proposal that increases the budget and will strengthen ERNs for rare and complex diseases."

"But the job is not done yet: it is now in the hands of the Germany Presidency of the EU Council to deliver on behalf of European citizens with an ambitious health programme, specifically recognising the place of rare diseases as a public health priority."

The limited number of patients in each country make EU collaboration in the area of rare diseases is of great added-value for patients. It serves as an example of the great achievements that stronger and structured EU action in the area of health can have. We therefore urge the final EU4Health programme to maintain the budget proposed by the European Parliament, and to go further in specifically recognising the place of rare diseases in European health policy.

We call now on the German Presidency fulfil its leading role by matching the ambition set out by the European Parliament in a budget that meets the expectations of European citizens. We stand by our colleagues in patient organisations and civil society in welcoming the ENVI's report. It is now time for Member States to align with the European Parliament to approve a much needed and well-funded EU4Health programme.

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## Contact

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## About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 930 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.

## About 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. 72% of rare diseases are genetic whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative. 70% of those genetic rare diseases start in childhood.

Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offerings 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.