

Statement

Have we already forgotten the lessons learnt from COVID-19?

European rare disease community calls for more ambitious health programme in the face of budget cuts to EU4Health Programme

24 July 2020, Brussels – EURORDIS-Rare Diseases Europe is calling on the European Commission, the negotiators of the European Parliament, and the German Presidency of the European Council to take action to reverse the European Council's drastic reduction of funding to the EU4Health programme.

EURORDIS - an alliance of over 900 patient organisations representing the 30 million people living with a rare disease in Europe - strongly supported the European Commission's proposal for the ambitious €9.4 billion standalone EU4Health Programme, which aligns with the want of 70% of European citizens to see more health-related actions at the European level¹.

In light of the current COVID-19 pandemic, it also showed a willingness to learn from the mistakes of the past and was a great step towards avoiding replicating them in the future. EURORDIS finds the European Council's recent decision to reduce the budget to €1.7 billion coming from the Multiannual Financial Framework (MFF) regrettable. It has a decisive impact on what can be achieved within this new framework.

Yann Le Cam, Chief Executive Officer, EURORDIS, commented, "We are very disappointed that even in the middle of a global pandemic, European leaders stepped away from an ambitious health programme rather than endorsing it. The Council's drastic reduction of the health programme is unacceptable, and we urge the Parliament to use its negotiating powers to reverse the decision. The revision of the EU4Health Programme within this new context is an opportunity to increase resources to protect EU citizens, in particular people living with a rare disease, by enhancing telemedicine, better infrastructures and at home therapies as we addressed in our <u>call for action</u> on how to protect our community post-confinement. Have we already forgotten the lessons learnt from COVID-19?"

The European Parliament (EP) has adopted Resolution 2020/2732 on the conclusions of the extraordinary European Council meeting of 17-21 July 2020 in which a call for support to the original Commission's proposal is reiterated and the EP expresses regret at the sizeable reduction in the budget. EURORDIS stands behind this resolution and is ready to support colleagues in the EP to ensure the programme is as ambitious as possible. Health is a priority for everyone, and the current situation has harshly reminded us of that. We therefore count on the European Commission, the negotiators of the European Parliament, and the German Presidency to make the right decision and to take actions to avoid mistakes of the past that have left us unprepared for the COVID-19 pandemic.

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¹ Recent Eurobarometer of the European Parliament (87.1)



About EURORDIS-Rare Diseases Europe

<u>EURORDIS-Rare Diseases Europe</u> 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.

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