Rare diseases: European Economic and Social Committee, a European strategy among national healthcare systems for the benefit of 36 million patients

Launching a European policy that can strengthen cooperation among national healthcare systems to provide better diagnoses, treatments and care to patients suffering from rare diseases: once again, it has been suggested to the European Commission by the European Economic and Social Committee (EESC), an advisory body that represents trade unions, businesses and other interest groups. Such strategy system would actually provide people suffering from rare diseases with the care they need in the member state in which the best treatments are available. Such policy is expected to strengthen cooperation among healthcare systems, so patients could have access to the most advanced knowledge and treatments wherever they are in the European Union. Since 2017, there have been 24 European Reference Networks (ERN) that, with the support of the European Commission, are an important mainstay of European cooperation among healthcare systems, but, as the EESC has been saying since 2009, "a global approach that reflects all the needs of people suffering from such diseases" is needed. Right now, 36 million people in the EU (8% of the population) suffer from one of the 7 thousand rare diseases that are currently known. In fact, there are no specific treatments or therapies for 95% of such conditions, since their complexity - just think of ALS, Amyotrophic Lateral Sclerosis – and the scarcity of knowledge and data make it difficult to work out a timely diagnosis and thus provide proper medical and social care.

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