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THE EUROPEAN JOINT PROGRAMME ON RARE DISEASES (EJP RD)

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The European Joint Programme on Rare Diseases (EJP RD), launched in January 2019, brings together the resources in rare diseases (RD) research at the national and European level, involving funders, universities, research organisations and infrastructures, hospitals and patient organisations representing over 130 institutions across 35 countries. Jointly funded by the European Commission and Member States over five years, its purpose is to create a comprehensive and sustainable ecosystem for RD research. The two main objectives of EJP RD are to improve the integration, efficacy, production, and social impact of research on RDs, and secondly to implement an efficient model of financial support for all types of RDs research. In order to successfully achieve its goals, EJP RD is structured into 'pillars'. Pillar 1 focuses on the financial support through the implementation of transnational calls for research projects into RDs (including basic, translational, clinical, social and health economic research topics), and a Networking support scheme to encourage sharing of knowledge on RDs. Pillar 2 aims to build a comprehensive, FAIR-compliant virtual platform pooling data and resources (e.g., registries, biobanks, databases, bioinformatics tools) allowing for these resources to be findable online via a central access point and accessible to the whole RD community. Pillar 3 aims at capacity building and patient empowerment through the provision of periodic training activities to the RD community, and will deliver an EU-wide education programme on transversal RD research to all interested stakeholders, fully available online via an e-learning platform. Pillar 4 aims at accelerating the translation of research outputs by creating and continuously developing online self-help resources for benefit of any RD researcher involved in translational research. It will also implement the support for funded RD projects by identifying results that can be supported for further funding and development, thereby enhancing their chance of reaching clinical implementation. In 9 months of its existence, the EJP RD already demonstrates how the centralised collaboration between different stakeholders advances RD research for the benefit of patients.

EJP RD, il Programma Europeo Congiunto sulle Malattie Rare

Malattie rare

Telethon Project (nr):

EJP RD

Disease Name:

Rare Diseases

Keywords: