

EU releases 144 mn euro for new rare disease research

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The European Union on Thursday pledged 144 million euros of fresh funding for research on rare diseases that currently affect some 30 million Europeans, the majority of them children.

The funding will go to 26 research projects in 29 countries "in Europe and beyond" to better diagnose and treat cardiovascular, metabolic and immunological disorders, the European Commission said.

"Most <u>rare diseases</u> affect children and most of them are devastating genetic disorders resulting in greatly reduced quality of life and premature death," said the EU commissioner for research and innovation Maire Geoghegan-Quinn.

"We hope that these new research projects will bring patients, their families and health professionals closer to a cure and support them in their daily battle with disease."

Among the different projects are a new "bioartificial" liver support system to treat <u>acute liver failure</u>, powerful data processing to develop novel diagnostic tools, biomarkers and screening strategies for therapeutic agents against rare kidney diseases, and the clinical development of a drug to treat alkaptonuria, a genetic disorder which leads to a severe and early-onset form of arthritis, heart disease and disability for which there is currently no effective treatment.

Many of the new projects will contribute to the International Rare



Diseases <u>Research Consortium</u> (IRDiRC), the biggest collective rare diseases research effort world-wide.

A disease is defined as rare in Europe when it affects not more than 1 in every 2,000 people.

But because there are between 6,000 to 8,000 rare diseases, together they affect a significant share of the population.

Most rare diseases have <u>genetic origins</u> whilst others are the result of infections, allergies and environmental causes. They are usually chronically debilitating or even life-threatening.

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