

Let's turn the spotlight on rare diseases and **RESEARCH**, the **HOPE** for all people with rare diseases to get back to building their lives with an eye to the **FUTURE**. Because behind the rare disease is a person who has a life to live.

DISCOVER WHAT WE DO FOR RARE DISEASE RESEARCH



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RARE DISEASE DAY®

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rarediseaseday.org
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#RARE
DISEASE
DAY

FEB 28
2025

MORE
THAN YOU CAN
IMAGINE

RARE DISEASES

are conditions that affect less than 1 in 2000 people in the EU, but collectively they impact millions worldwide. Often affecting vulnerable populations like children, these diseases may be severe, invisible and lack of adequate treatments. Therefore, rare diseases challenge science and medicine

WE TURN RESEARCH INTO HOPE FOR THOSE FACING RARE DISEASES

PARTNERING IN EUROPE FOR RARE DISEASES RESEARCH



COLLABORATIVE GLOBAL RESEARCH

Working with international partners to bring real solutions to rare diseases.



INNOVATING FOR THE FUTURE

Pushing the boundaries of technology, diagnosis, and treatment with advanced research projects.



SUPPORTING ORPHAN MEDICINES DEVELOPMENT

Creating pathways for new therapies that bring hope to patients worldwide.

EVERY STEP FORWARD IS PROGRESS FOR ALL

RESEARCH AND INNOVATION

We play a key role to develop a European ecosystem of research, global data sharing and collaborations finally promoting prevention, diagnosis, and treatment for rare diseases.



Through innovative methodology tool based on clinical data and in-silico models, we contribute to improve a regulatory-sounded development of paediatric and orphan medicines.



We contribute to improve the development of innovative medical devices for children affected by rare diseases.



We are involved in a national project which aims to integrate biosamples and data from biobanks, registries, and health records through modelling and networking.

BETTER

ADVANCING IN THE FIELD OF RARE HAEMOGLOBINOPATHIES



Focusing on haemoglobinopathies, we work together in international networks, projects and initiatives to drive research forward.

SHAPING A FUTURE WITHOUT BARRIERS

