



Inclusion of rare diseases in scientific research

**Rare Disease day policy event
at the United Nations**

21 February 2019

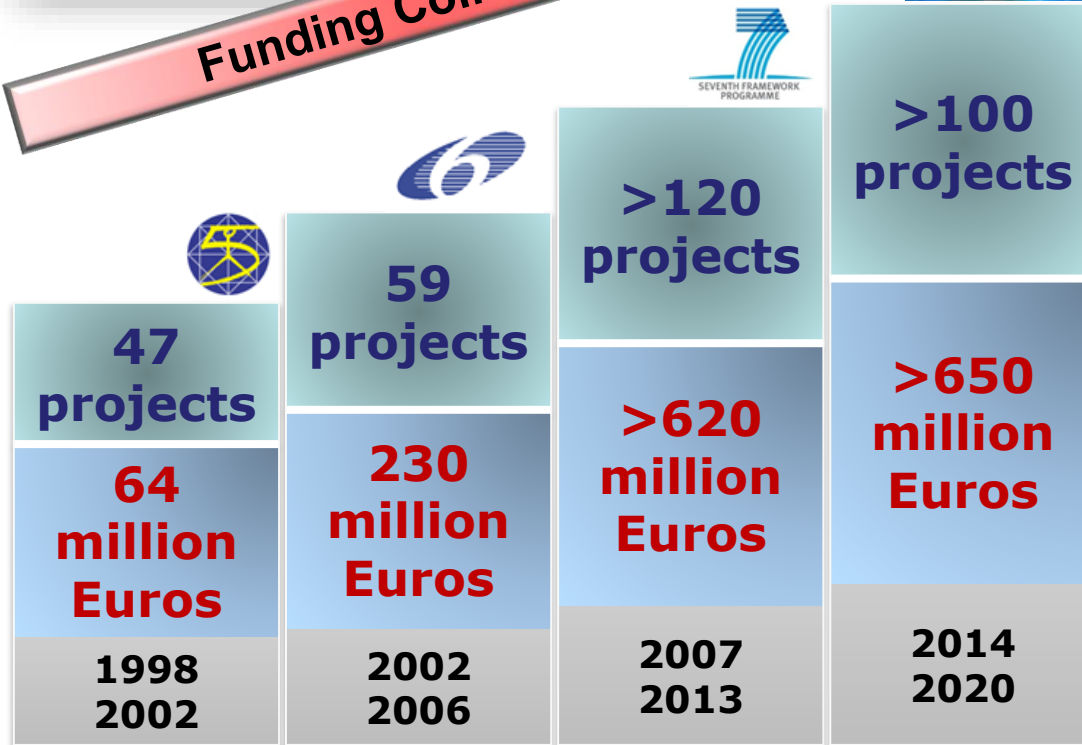
**Irene Norstedt, Acting Director
Health Directorate
Directorate-General For Research and Innovation
European Commission**

*Research and
Innovation*

The EU funding of rare disease research



Funding Collaborative Research



International collaboration



over 50 members: funders, industry, patients

✓ Launch in 2011

- All patients to receive the diagnosis within one year
- 1000 new therapies
- Methodologies to assess impact of diagnoses and therapies on patients by 2027

Policies and guidelines to implement goals

New therapies and better diagnostics

H2020 collaborative projects, calls 2015 and 2017



TRACE

UshTher



TUDCA-ALS



EUROPEAN JOINT PROGRAMME ON RARE DISEASES

EJP RD



**EU contribution
55M EUR for
2019-2023**

- Research and innovation pipeline for rapid translation of research results into clinical applications and uptake in healthcare for the benefit of patients
- Research funders, universities, research institutes, research infrastructures, hospitals from ERNs and patient organisations from 35 countries (including 27 EU Member States, seven Associated Countries and Canada)
- Joint Transnational Calls for rare diseases research projects: JTC 2019 launched
- Virtual platform for rare diseases research data, information and tools
- Capacity building, training, facilitation of partnerships, validation of new methods for clinical trials

**RESEARCH
FUNDING**

**COORDINATED
ACCESS TO
DATA &
SERVICES FOR
RESEARCH**

**CAPACITY
BUILDING &
EMPOWERMENT**

**ACCELERATING
TRANSLATION
OF RESEARCH &
THERAPY
DEVELOPMENT**

www.ejprarediseases.org

Commission proposal for
Horizon Europe

THE NEXT EU RESEARCH & INNOVATION
PROGRAMME (2021 – 2027)

#HorizonEU



Rationale for EU funded health R&I

*Everyone has the right to timely access to affordable healthcare of good quality**

Newly emerging or persisting health challenges:

- Threats to citizens and public health
- Sustainability of social and health care systems
- Competitiveness of EU's health and care industry

These challenges are complex, interlinked and global

The Health Cluster builds links between:

- Discovery, clinical, epidemiological, environmental and socio-economic research
- Academia – industry – healthcare providers – patients
- Expertise within the EU and beyond



* EU Pillar of Social Rights, UN SDGs

Health cluster : Six main areas of intervention



Health throughout
the Life Course



Environmental and Social
Health Determinants



Non-communicable
and Rare Diseases



Infectious diseases



Tools, Technologies
and Digital Solutions
for Health and Care



Health Care Systems



Thank you

<http://ec.europa.eu/programmes/horizon2020/>

<http://ec.europa.eu/research/health>

<http://ec.europa.eu/horizon-europe>

More information on funded projects: <https://cordis.europa.eu/projects/en>

Calls for proposals:

<http://ec.europa.eu/info/funding-tenders/opportunities/portal/screen/programmes/h2020>