ERDERA
European Rare Diseases
Research Alliance

Making Europe a world-leader in rare diseases research and innovation

Connecting the dots in the rare diseases research ecosystem

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Co-funded by the European Union

ERDERA has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement N°101156595.
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ERDERA

EUROPEAN **RARE DISEASES** RESEARCH ALLIANCE

2024 – 2034

Co-funded by the European Union

ERDERA proposal n°101156595 is under grant preparation and will be funded under call HORIZON-HLTH-2023-DISEASE-07 as a COFUND Action.

EJP RD

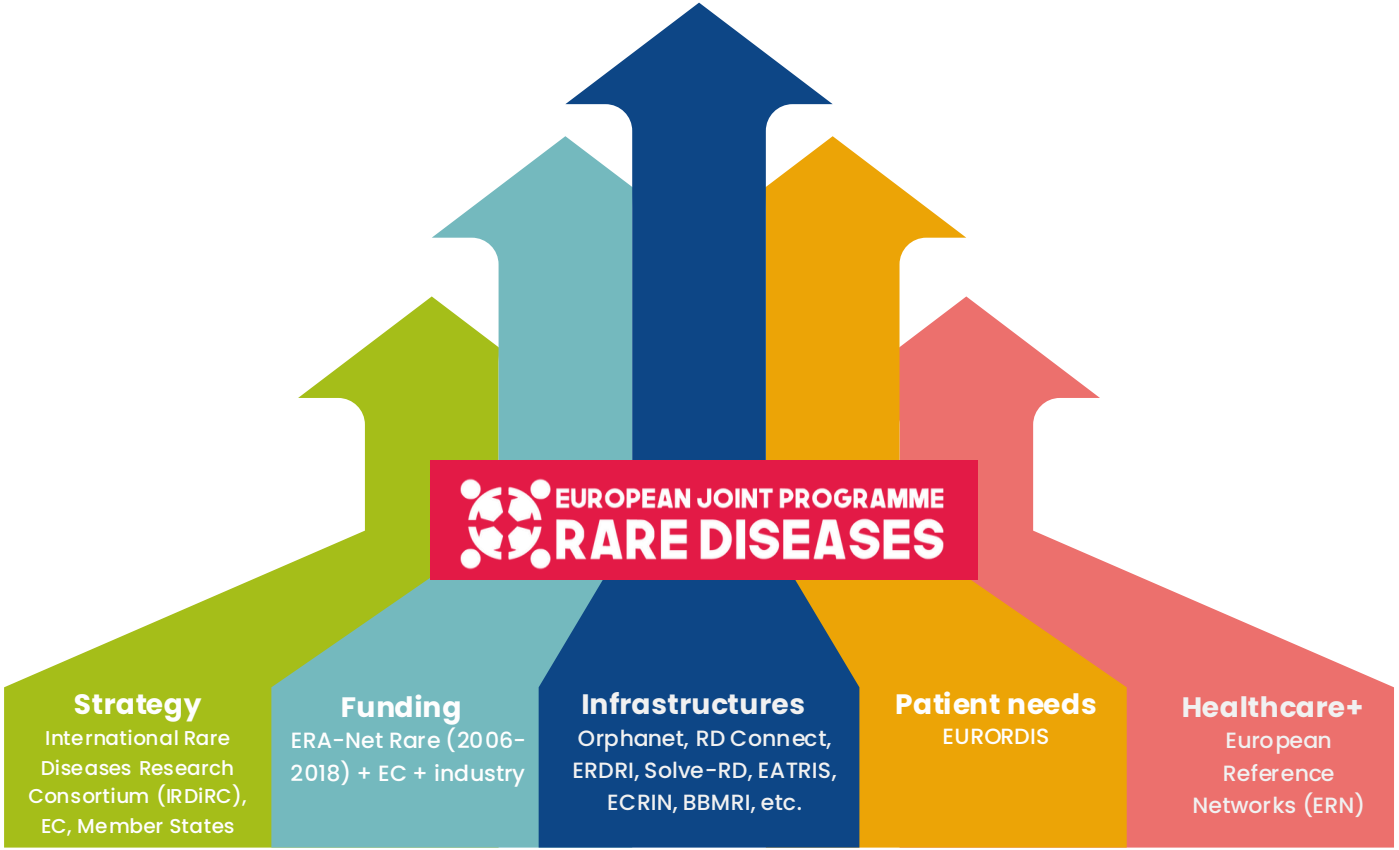


ERDERA

EUROPEAN **RARE DISEASES** RESEARCH ALLIANCE


WHEN?


WHERE?


EUROPEAN JOINT PROGRAMME
RARE DISEASES
Strategy
International Rare Diseases Research Consortium (IRDiRC), EC, Member States
Funding
ERA-Net Rare (2006-2018) + EC + industry
Infrastructures
Orphanet, RD Connect, ERDRI, Solve-RD, EATRIS, ECRIN, BBMRI, etc.
Patient needs
EURORDIS
Healthcare+
European Reference Networks (ERN)



Why is ERDERA a major achievement for rare diseases?

ERDERA
European Rare Diseases Research Alliance

Remaining unmet needs





95%

of RDs are disregarded in terms of research & effective treatment options

50%

of RD patients still do not have confirmed molecular diagnosis

4

years - is an average time to be diagnosed when RD is known

52%

of RD patients and carers, RD translates into severe impact on their daily life

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37 Countries

25 EU member states

9 associated countries

3 non-EU

178 Organisations

40 funders

81 research performing organisations

9 patients' organisations

3 research infrastructures

22 private for-profit partners (industry & SME)

23 other (univ, hospital, non-profit, public administration)

Involvement of ERNs

BOND
CRANIO
ENDO
EpiCare
ERKNet
ERNICA
EURO-NMD / DDF
RND
EuroBloodNet
eUROGEN
EYE
ITHACA
MetabERN

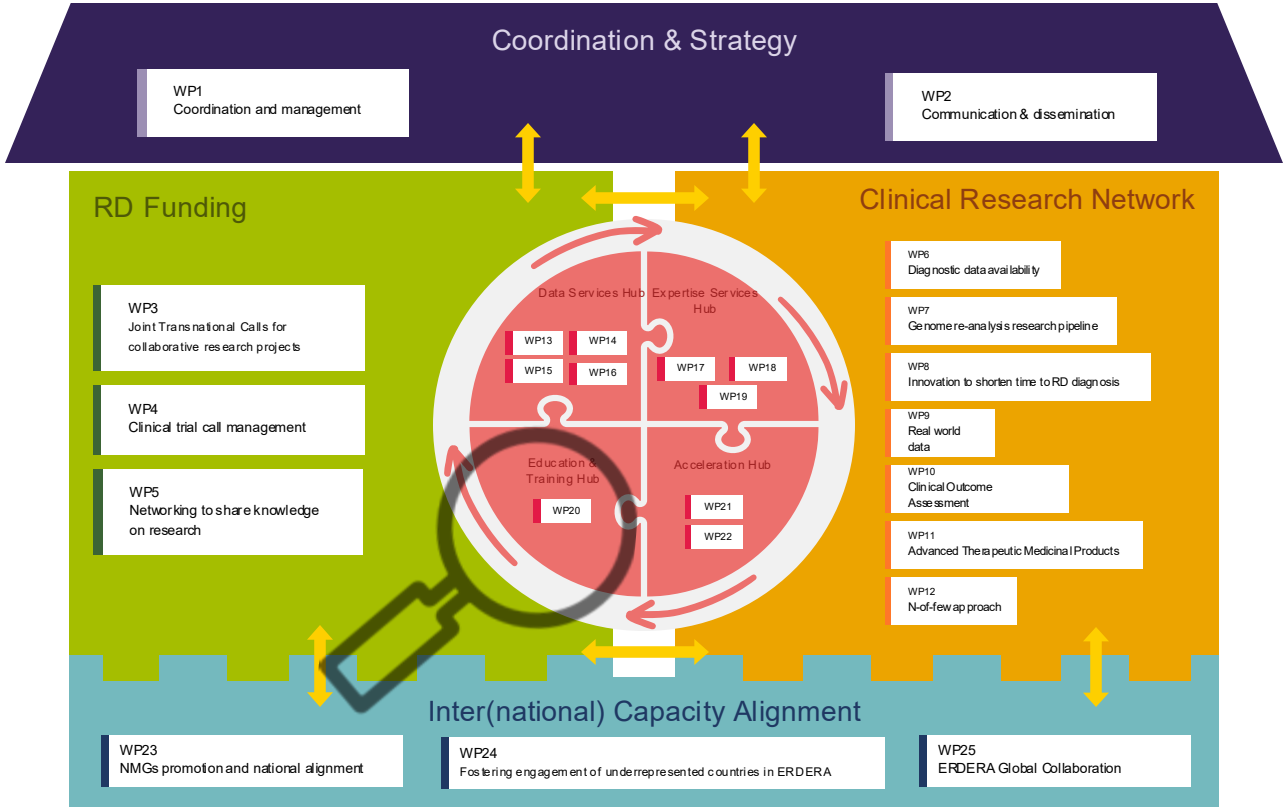


EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES
Share. Care. Cure.

European Reference Networks

European Commission | Health





WP13
Rare Diseases-Virtual Platform (RD-VP): Finding and accessing the data ecosystem

WP14
Data readiness services

WP15
Data sharing and analysis services

WP16
Knowledge bases and ontologies for RD research

WP17
Mentoring and consultancy

WP18
Regulatory support service

WP19
Methodological Support

WP20
Education and training in rare diseases research

WP21
Technology accelerator

WP22
Public-Private Collaboration Accelerator

ERDERA European Rare Diseases Research

WP20: Education and Training in RD research

- **Task 20.1 –** Patients and young researchers' trainings
- **Task 20.2-** Identification and fulfilment of training needs
- **Task 20.3 -** RD research training for multistakeholder communities
- **Task 20.4-** European Curriculum on RD research

WP20
Education and Training on RD Research

ST20.1.2. Training workshops for paediatric patients (M1-M12)

STL: TEDDY; Contributors: c4cS, IMAGINE, EURORDIS.

This ST will consist in developing a yearly age-tailored training for young people (12-18 years old).

First Edition ERDERA – Young Patients Training, Athens 2-3 may 2025

Video
AGENDA
Speaker
Training Session



ERDERA European Rare Diseases Research Alliance

WP20
Education and Training on RD Research





European **Rare Diseases** Research Alliance

Thank you!

Rima NABBOUT, MD, PhD

Donato BONIFAZI, TEDDY Chair

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