ERICA - ERN Rare dIsease research Coordination & support Action

Luca Sangiorgi, MD, PhD
IRCCS Istituto Ortopedico Rizzoli

ERN BOND

European Reference Network on rare BONe Diseases

European Reference Networks

Co-funded by the European Union
ERN BOND Specific Grant Agreement no. 847078

Presentation of ERICA

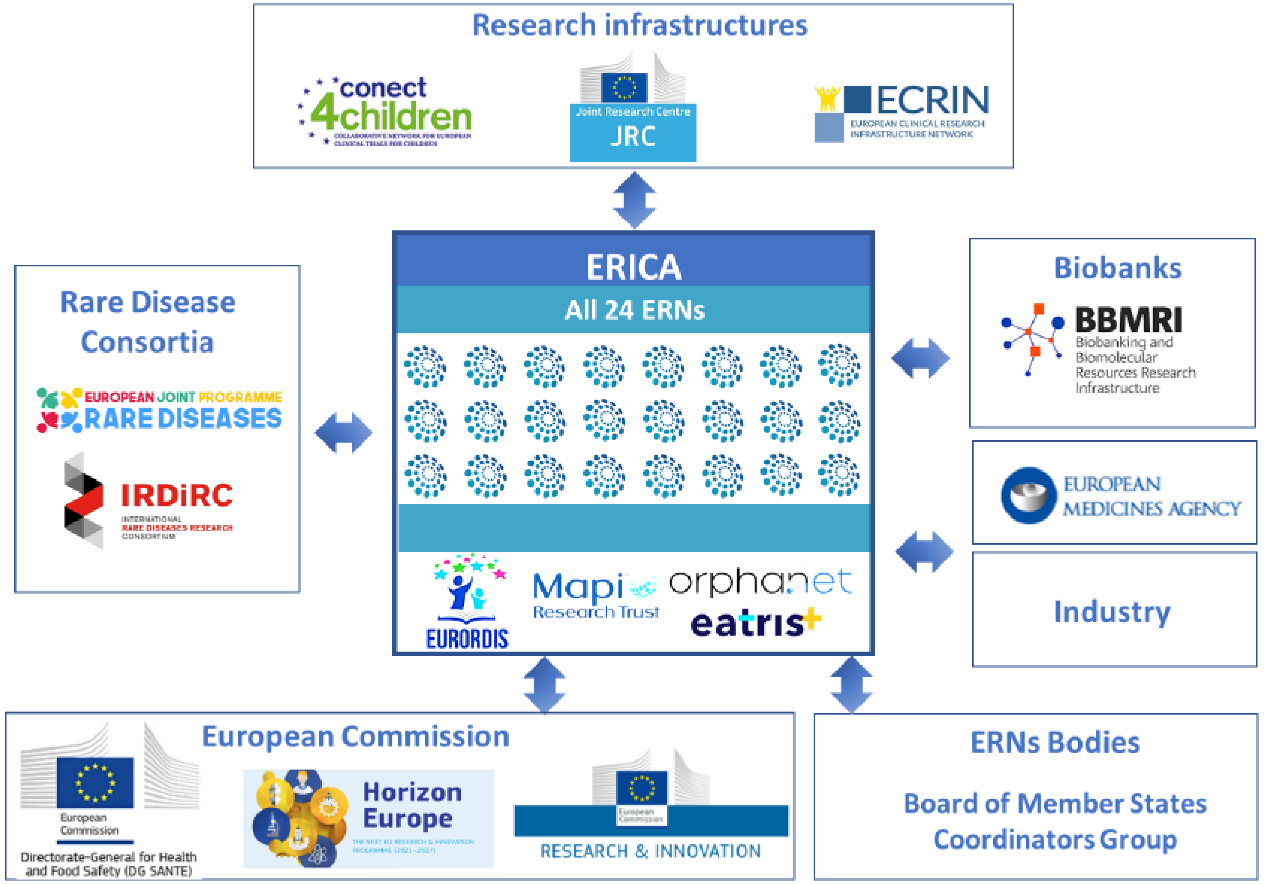
ERICA is a consortium in which all 24 ERNs take part. Its aim is to build on the strength of the individual ERNs and create a **platform that integrates all ERN's research and innovation capacity**.

Through knowledge sharing, engagement of transdisciplinary research groups working across the global health spectrum ERICA's objective is to result in **safe, accessible and efficient access of therapies** for the benefit of patients suffering from rare diseases and conditions.

ERICA & the rare disease research ecosystem

Positioning of ERICA within the RD research ecosystem, connected via the ERN Research Working group with the European Commission.

ERICA is also linked to the EJP and IRDIRC, the research infrastructures, and last but not least, with biobanks, EMA, and Industry.



Research infrastructures

ERICA

All 24 ERNs

Rare Disease Consortia

Biobanks

Industry

European Commission

ERNs Bodies

Board of Member States Coordinators Group

Work packages and activities

ERICA comprises 6 work packages, devoted to

- coordination and strategic planning (WP1),
- data collection, integration and sharing (WP2),
- tools to promote patient-centred research (WP3),
- support for clinical trials and epidemiological research (WP4),
- translational research and innovation (WP5),
- dissemination of ERN research activities (WP6)

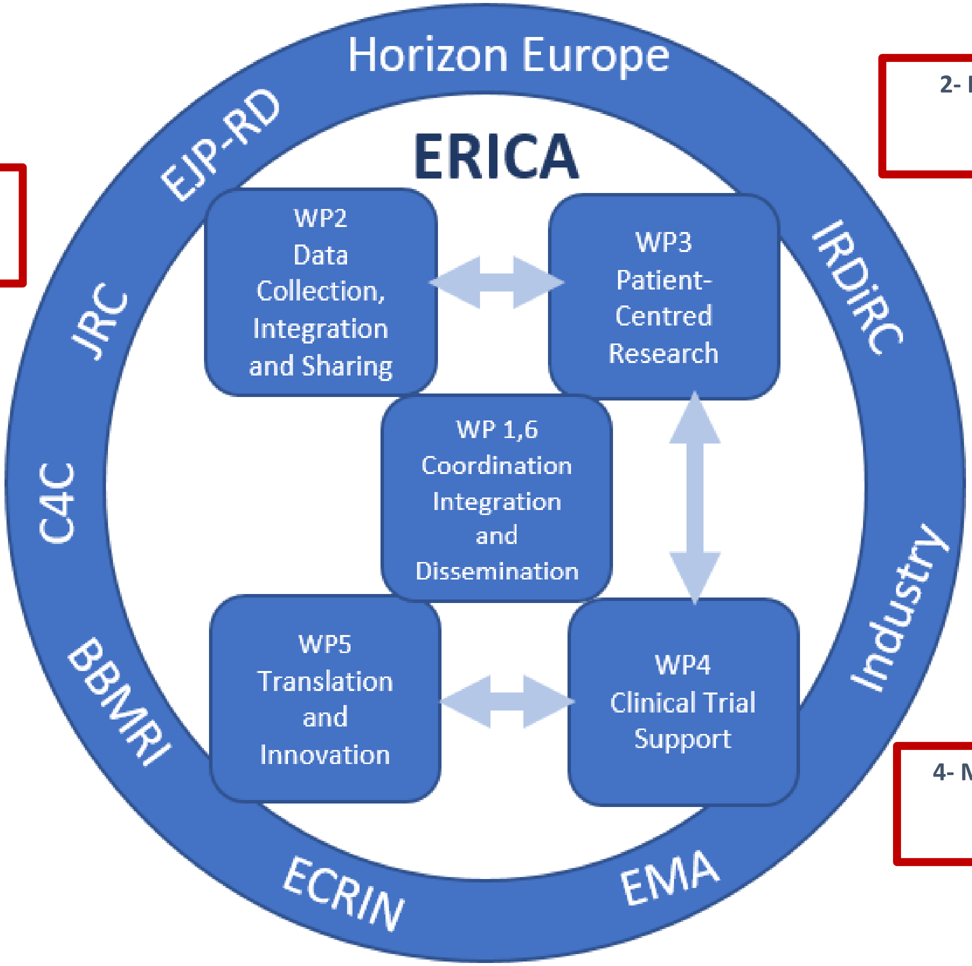
ERN BOND is leader of the WP4

Co-funded by the European Union
ERN BOND Specific Grant Agreement no. 847078

Specific objectives and collaborative outreach

1 - Record, coordinate, and disseminate ERN clinical research activities in line with ERICA's strategic positioning (WP1, WP6)

5- Encourage methodology sharing and increase innovation potential of ERNs (WP4, WP5)



2- Facilitate collection, sharing and analysis of clinical research data within and between ERNs (WP2, WP4)

3- Advance patient-centred research and outcomes monitoring by promoting identification and application of patient-centred outcome measures for RD (WP3)

4- Map, integrate and link ongoing activities with regards to facilitating Europe-wide multicentre clinical trials (WP4)

Work of the WP4 – Clinical Trial Support

Activities in this work package will be geared towards:

- Create a strong ERN overarching clinical trials network and thereby promote the EU as an attractive location to run RD clinical trials.
- Avoid unnecessary duplication of studies/resources already available at the EU level;
- Ensure that the patient voice is systematically included in clinical trial design

Connection with other RD research consortia currently conducting/planning clinical trials (e.g. RECOMB) is foreseen as well as initiatives that are currently on-going in the paediatric field via the Conect4Children network (c4c).

WP4 Objectives

Objectives:

- To foster clinical trial research implementation.
- To increase awareness of activities/opportunities available from stakeholders

(EJP-RD BBMRI, EMA, IRDiRC).

- To build a solid foundation for a Patient Engagement framework on clinical trials

European Reference Networks
Co-funded by the European Union
ERN BOND Specific Grant Agreement no. 847078

European
Reference
Networks
for rare or low prevalence
complex diseases

Network
Bone Disorders (ERN BOND)

Thank you

For more information

Email
info@ernbond.eu

Website
http://ernbond.eu/

ERN BOND

European Reference Network on rare BONe Diseases

This presentation is generated within the European Reference Network on rare BONe Diseases which is partly co-funded by the European Union (Specific Grant Agreement no. 847078)