The European Reference Networks Coordinators Group (ERN-CG)

Maurizio Scarpa, ERN-CG Chair, Coordinator of the European Reference Network for Rare Inherited Metabolic Diseases (MetabERN), on behalf of the ERN Coordinators.

What is the ERN-CG ?

The European Reference Networks Coordinators Group (ERN-CG) brings together the Coordinators of the 24 approved European Reference Networks (ERNs). The ERN-CG was officially formalized by the European Commission on April 26 2017 during the first meeting of the 24 established European Reference Networks.

What Does the ERN-CG do?

The ERN-GC focuses on strategic issues relevant to the ERNs implementation, functioning and governance and provides advice to the European Commission and Member States when needed on matters related to the ERNs and RD Policy.

The ERN-CG has already produced documents on monitoring and third parties interactions. 5 Registries have been granted as a start up for a European Rare Diseases Registry.

What are the Working Methods of the ERN-CG?

The ERN-CG agreed to organize 6 Working Groups based on important topics to be discussed with the European Commission and the Board of Member States.

Furthermore, a special task aimed to discuss about Integration with the National Health System, Legal Entity and Sustainability has been set up.

The ERN-CG agreed to select a Chair (Spokesman) as a rapporteur of Working Groups with the European Commission and the Board of Member States.

ERN-CG Working Groups and its Achievements

IT and data sharing

Chair: Ruth Landestein (ERN PaedCan)

Research (4 sub strands)

Chairs: Luca Sangiorgi (BOND ERN), Eduardo López Granados (TRANSPANTCHILD), Alberto Pereira (ENDOERN), Franz Schäffer (ERK NET)

Knowledge generation: Training, education, capacity building, Guidelines

Chair: Paolo Casali (ERN EURACAN)

Ethics & legal issues: Data protection, informed consent, etc.

Chair: Nicoline Hoogerbrugge (ERN GENTURIS)

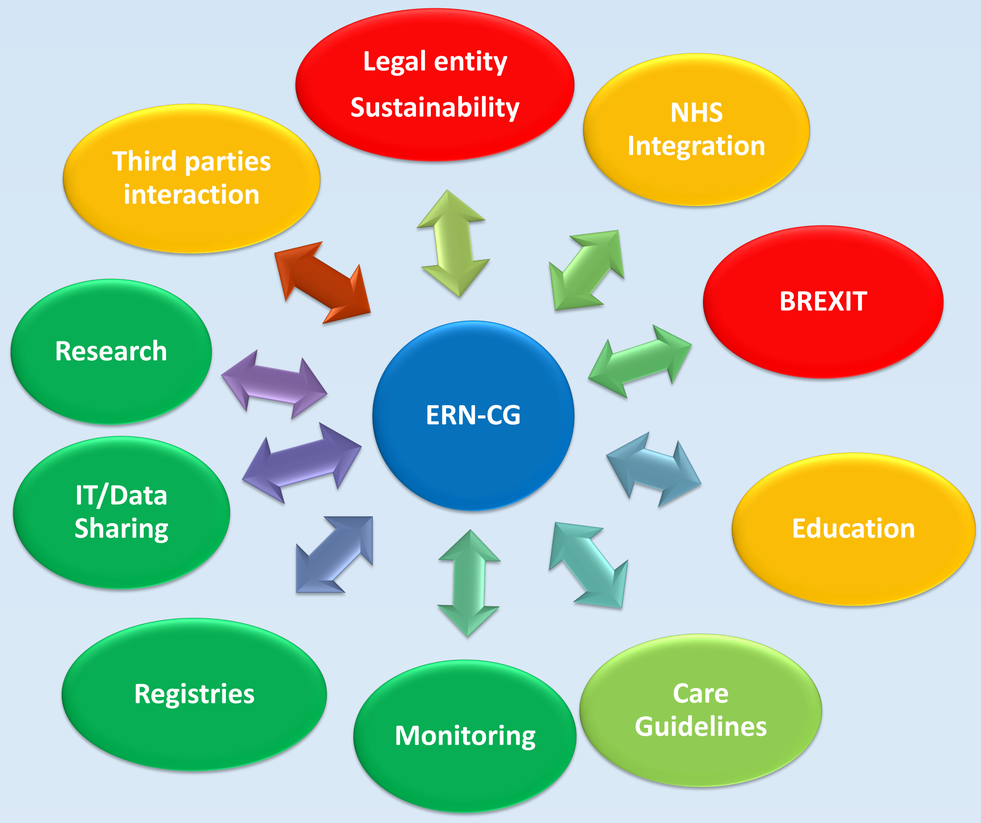
Cross-border healthcare and business continuity

Chairs: Holm Grässner (ERN-RND) & Kate Bushby (EURO NMD)

Monitoring, assessment & quality improvement

Chair: Christopher Chapple (ERN EUROGEN)

Special projects: **National Health System Integration, Sustainability,**
Chair: Maurizio Scarpa (METABERN)



ERN-CG and the Board of Member States

The ERN-CG is working in close contact with the Board of Member States to optimize the impact of the ERNs in the Member States and the implementation of the Cross Border Healthcare Directive 2011/24/EU. It is playing a crucial role in facilitating and harmonizing the sharing of expertise for the common benefit and has already demonstrated that it constitutes an invaluable and valid instrument for the ERNs.

Contact Information

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