

THE EUROPEAN REFERENCE NETWORK: AIMS, TASKS AND ACHIEVEMENTS

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Coordinator,***

European Reference Network Bone Rare Diseases ERN BOND

2018 annual workshop of the European network of paediatric research at the EMA (Enpr-EMA)

Thursday 7 June 2018



THE ORIGIN OF THE ERNS



The road to ERNs



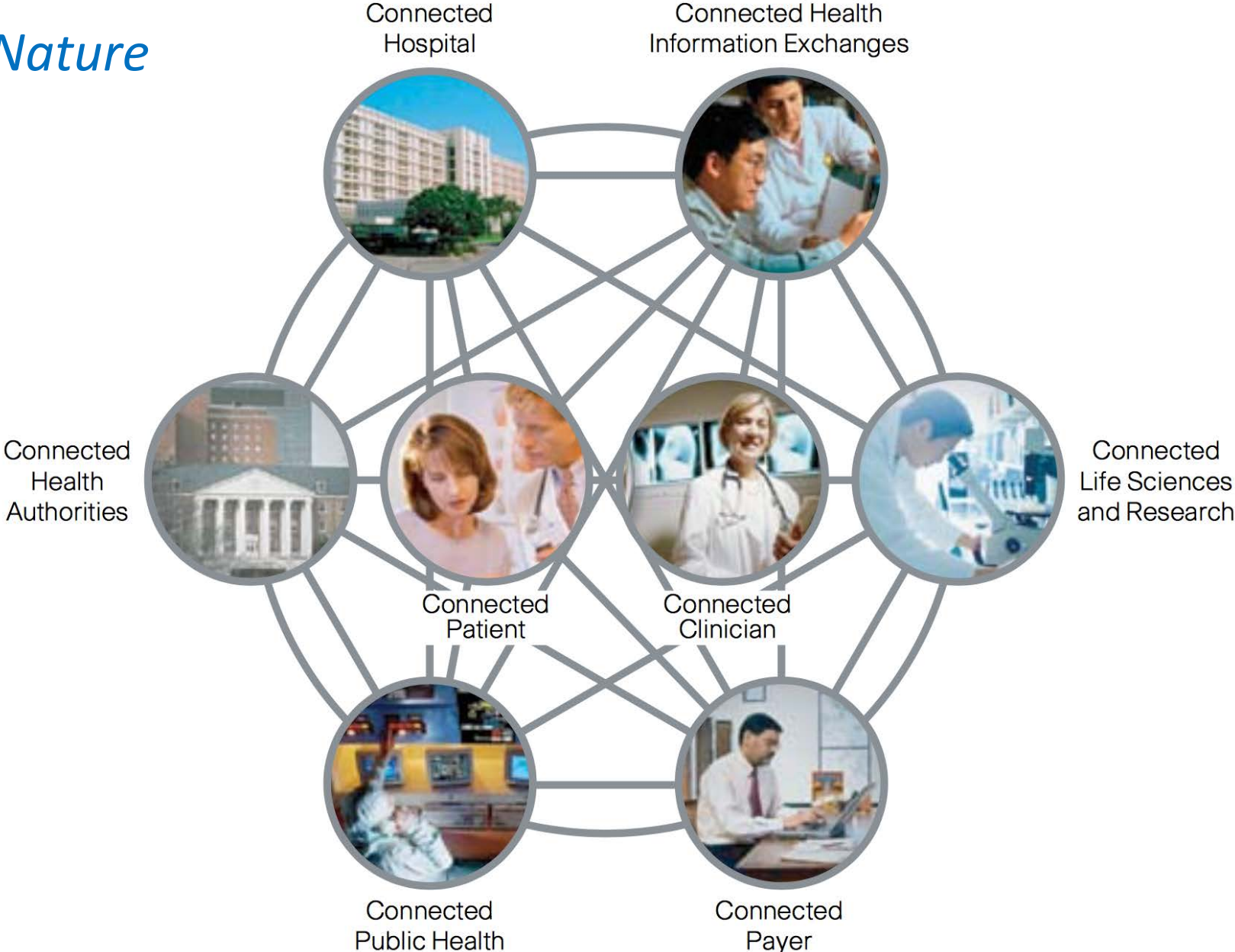
Grouping Rare Diseases In Thematic Networks

- Rare immunological and auto-inflammatory diseases
- Rare bone diseases
- Rare cancers* and tumours
- Rare cardiac diseases
- Rare connective tissue and musculoskeletal diseases
- Rare malformations and developmental anomalies and rare intellectual disabilities
- Rare endocrine diseases
- Rare eye diseases
- Rare gastrointestinal diseases
- Rare gynaecological and obstetric diseases
- Group on Cancer Control

- Rare haematological diseases
- Rare craniofacial anomalies and ENT (ear, nose and throat) disorders
- Rare hepatic diseases
- Rare hereditary metabolic disorders
- Rare multi-systemic vascular diseases
- Rare neurological diseases
- Rare neuromuscular diseases
- Rare pulmonary diseases
- Rare renal diseases
- Rare skin disorders
- Rare urogenital diseases

*Note: The networking of rare cancers is currently under discussion in EC Expert

ERNs Mimick Nature



1. ERN BOND	European Reference Network on Rare Bone Disorders
2. ERN CRANIO	European Reference Network on Rare craniofacial anomalies and ENT disorders
3. Endo-ERN	European Reference Network on Rare Endocrine Conditions
4. ERN EpiCARE	European Reference Network on Rare and Complex Epilepsies
5. ERKNet	European Rare Kidney Diseases Reference Network
6. ERN RND	European Reference Network on Rare Neurological Diseases
7. ERNICA	European Reference Network on Rare inherited and congenital anomalies
8. ERN LUNG	European Reference Network on Rare Respiratory Diseases
9. ERN Skin	European Reference Network on Rare and Undiagnosed Skin Disorders
10. ERN EURACAN	European Reference Network on Rare Adult Cancers (solid tumours)
11. ERN EuroBloodNet	European Reference Network on Rare Haematological Diseases
12. ERN EURO-NMD	European Reference Network for Rare Neuromuscular Diseases
13. ERN EYE	European Reference Network on Rare Eye Diseases
14. ERN GENTURIS	European Reference Network on Genetic Tumour Risk Syndromes
15. ERN GUARD-HEART	European Reference Network on Uncommon And Rare Diseases of the HEART
16. ERN ITHACA	European Reference Network on Rare Congenital Malformations and Rare Intellectual Disability
17. MetabERN	European Reference Network for Rare Hereditary Metabolic Disorders
18. ERN PaedCan	European Reference Network for Paediatric Cancer (haemato-oncology)
19. ERN RARE-LIVER	European Reference Network on Rare Hepatological Diseases
20. ERN ReCONNECT	Rare Connective Tissue and Musculoskeletal Diseases Network
21. ERN RITA	Rare Immunodeficiency, Autoinflammatory and Autoimmune Diseases Network
22. ERN TRANSPLANT-CHILD	European Reference Network on Transplantation in Children
23. VASCERN	European Reference Network on Rare Multisystemic Vascular Diseases
24. ERN eUROGEN	European Reference Network on Rare and Complex Urogenital Diseases and Conditions

European Reference Networks Conference

& ERN Kick-off meeting

Vilnius, Lithuania, 9-10 March 2017

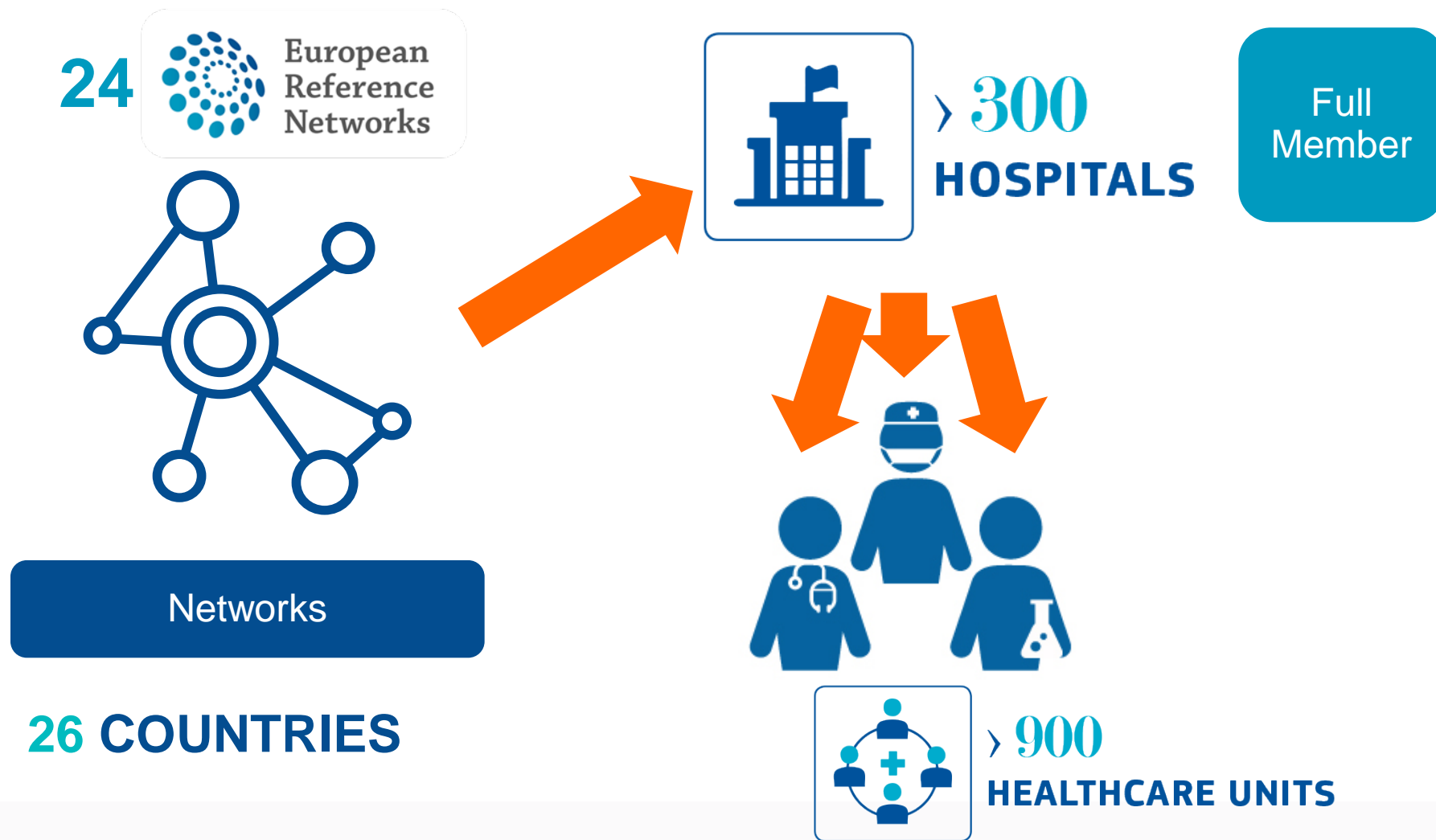


European
Reference
Networks





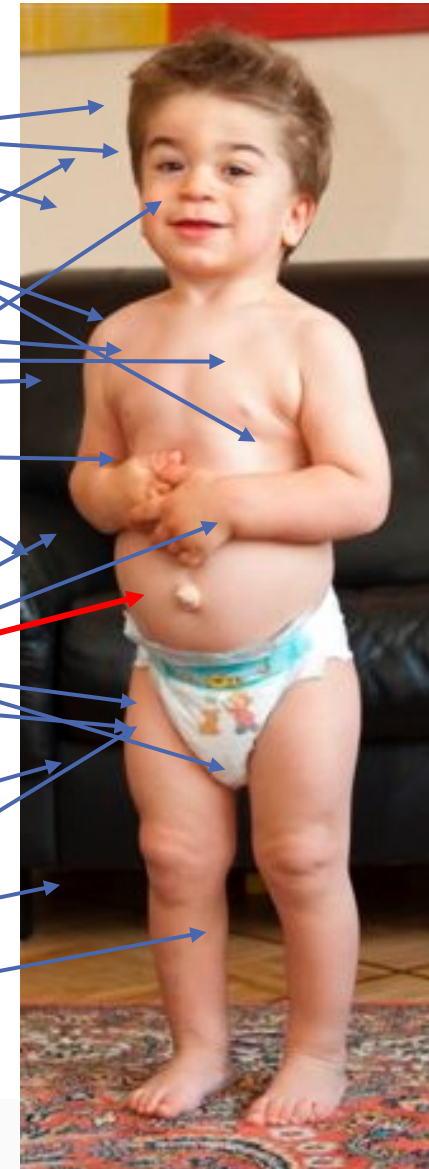
Coordination is important since ...



Coordination is in the interest of patients



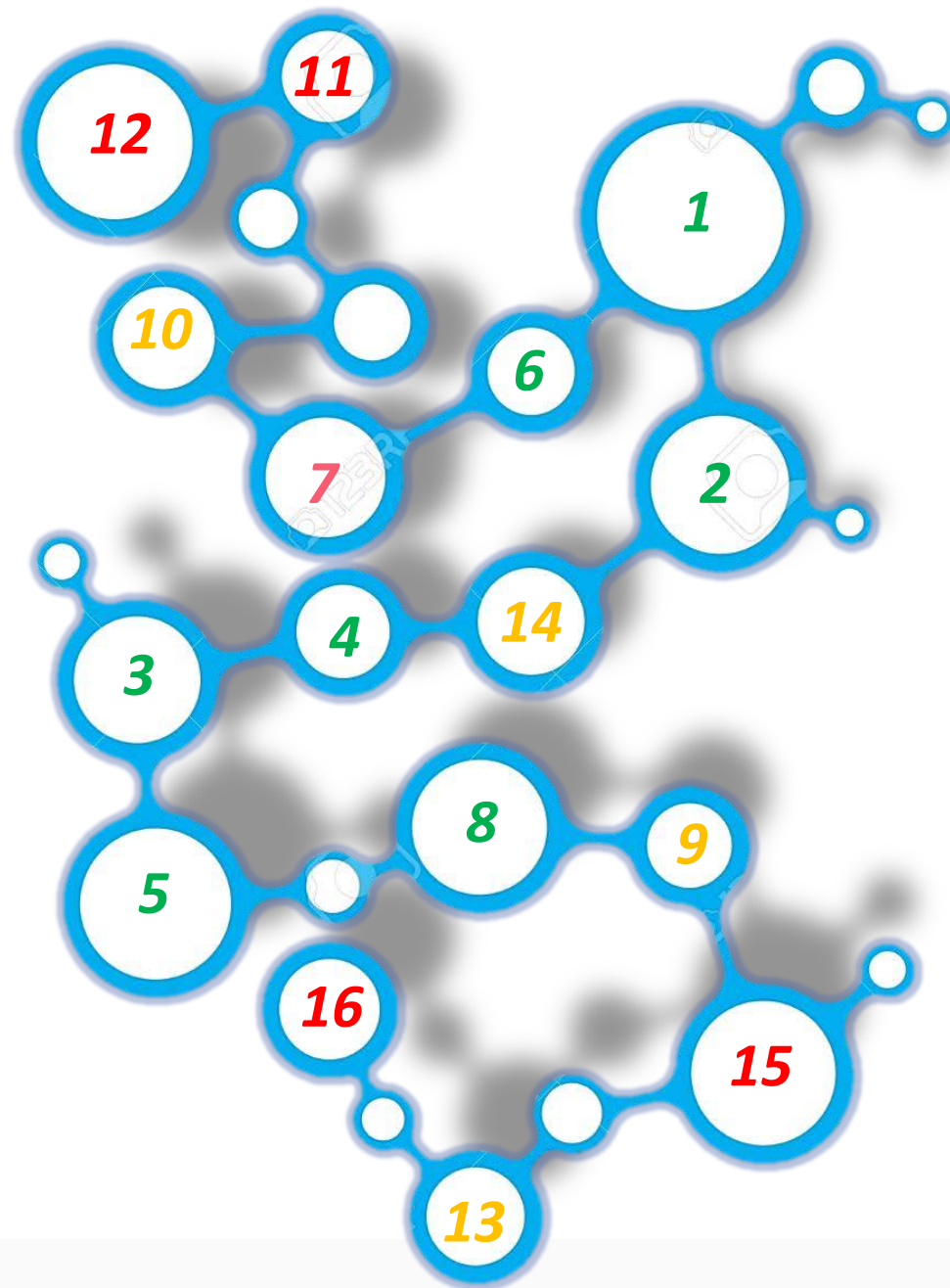
- 1. ERN BOND
- 2. ERN CRANIO
- 3. Endo-ERN
- 4. ERN EpiCARE
- 5. ERKNet
- 6. ERN RND
- 7. ERNICA
- 8. ERN LUNG
- 9. ERN Skin
- 10. ERN EURACAN
- 11. ERN EuroBloodNet
- 12. ERN EURO-NMD
- 13. ERN EYE
- 14. ERN GENTURIS
- 15. ERN GUARD-HEART
- 16. ERN ITHACA
- 17. MetabERN**
- 18. ERN PaedCan
- 19. ERN RARE-LIVER
- 20. ERN ReCONNET
- 21. ERN RITA
- 22. ERN TRANSPLANT-CHILD
- 23. VASCERN



24. ERN eUROGEN

The ERN Interactome: Coordination of the Activities

- 1. ERNs COORDINATION*
- 2. PATIENT COMMITMENT*
- 3. DISEASE IDENTIFICATION*
- 4. REGISTRY*
- 5. DATA SHARING*
- 6. COMMUNICATION/AWARENESS*
- 7. EDUCATION*
- 8. SHARED VIRTUAL COUNSELLING*
- 9. NETWORK OF SPECIALISTS*
- 10. INSTITUTIONAL STAKEHOLDERS*
- 11. PAYERS*
- 12. NATIONAL HEALTH SYSTEMS/NPRD*
- 13. RESEARCH COORDINATION*
- 14. GUIDELINES/PATIENT PATHWAYS*
- 15. STANDARD OPERATING PROCEDURES*
- 16. QUALITY INDICATORS*





The *ERNCG Achievements* Group

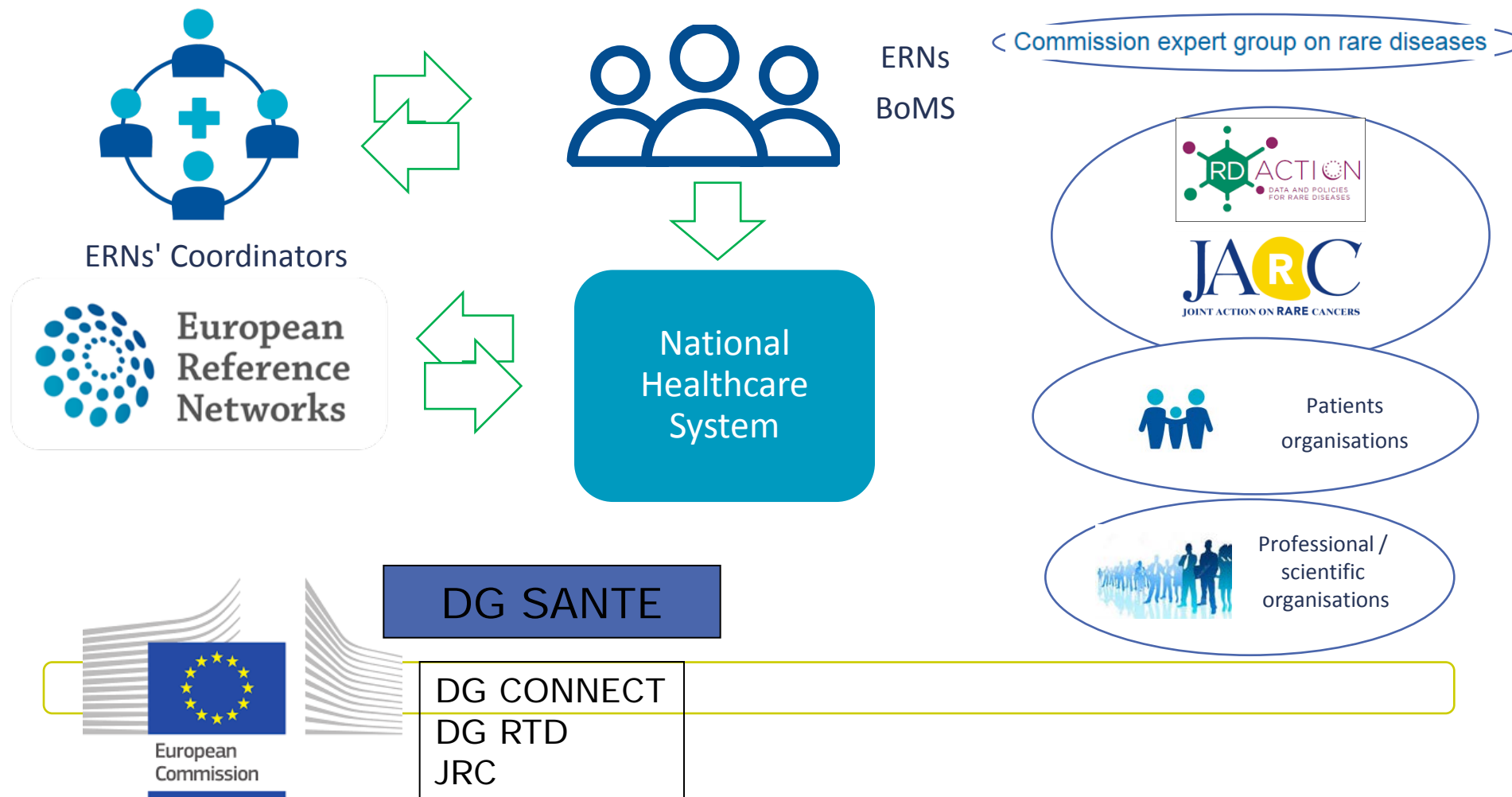
Chair: Maurizio Scarpa, MetabERN

Vice-Chair: Franz Schäfer, ERKNET

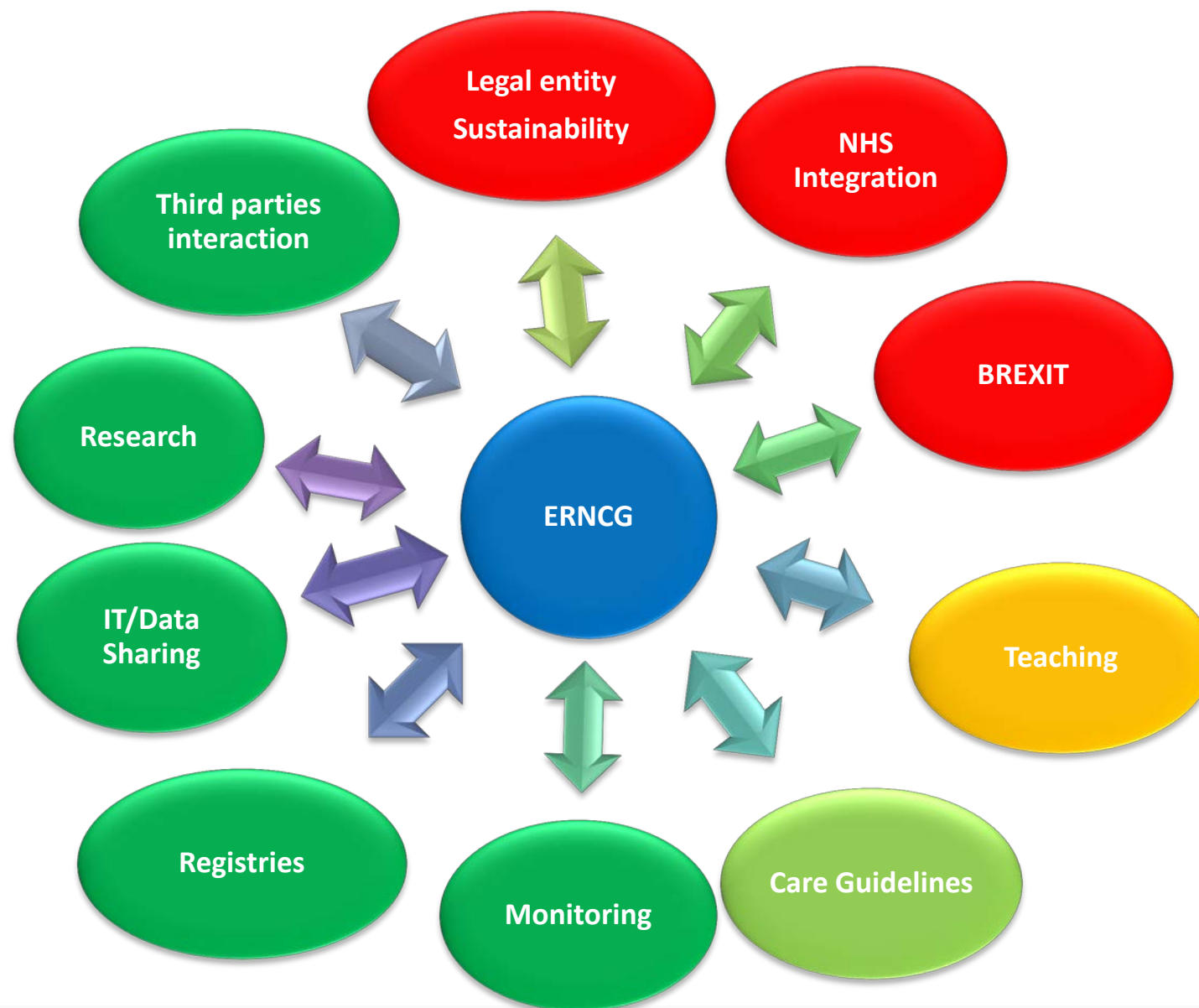
Board: WG Coordinators

WG	LEADERSHIP
IT & DATA-SHARING	Ruth Ladenstein, ERNPaedcan
RESEARCH	Eduardo López Granados, ERN TransplantChild
LEGAL ASPECTS, DATA PROTECTION & ETHICS	Nicoline Hoogerbrugge, GENTURIS
CROSS-BORDER HEALTHCARE AND BUSINESS CONTINUITY	Holm Graessner, ERN-RND; Kate Bushby, EURO NMD
MONITORING & ASSESSMENT	Christopher Chapple, EUROGEN
GUIDELINES, EDUCATION, TRAINING	Paolo Casali, ERN EURACAN
SPECIAL PROJECTS: NHS INTEGRATION SUSTAINABILITY	Maurizio Scarpa, MetabERN

ERNCG and Actors involved in the ERN implementation



Achievements



Conclusions

- ERNs are NOT a project or a program, they are a CONCEPT and represent the major achievement of the European spirit of collaboration, sharing and health investment in the field of rare diseases
- ERNs group the most acknowledged centers of excellence in Europe (300 hospitals and over 1000 specialised units), all sharing the same level of commitment and interest for rare diseases
- ERN Coordinators organized themselves and are working together to accelerate the best operability of the ERNs.
- The ERNCG is a THINKTANK which is facing, discussing and proposing programs to decrease the diverse treatment of patients in EU.
- Important documents have been generated showing the commitment of the group and the importance of working together.
- The ERNCG will impact not only the harmonization of the ERNs but also at political, legal, administrative and policy making levels.