

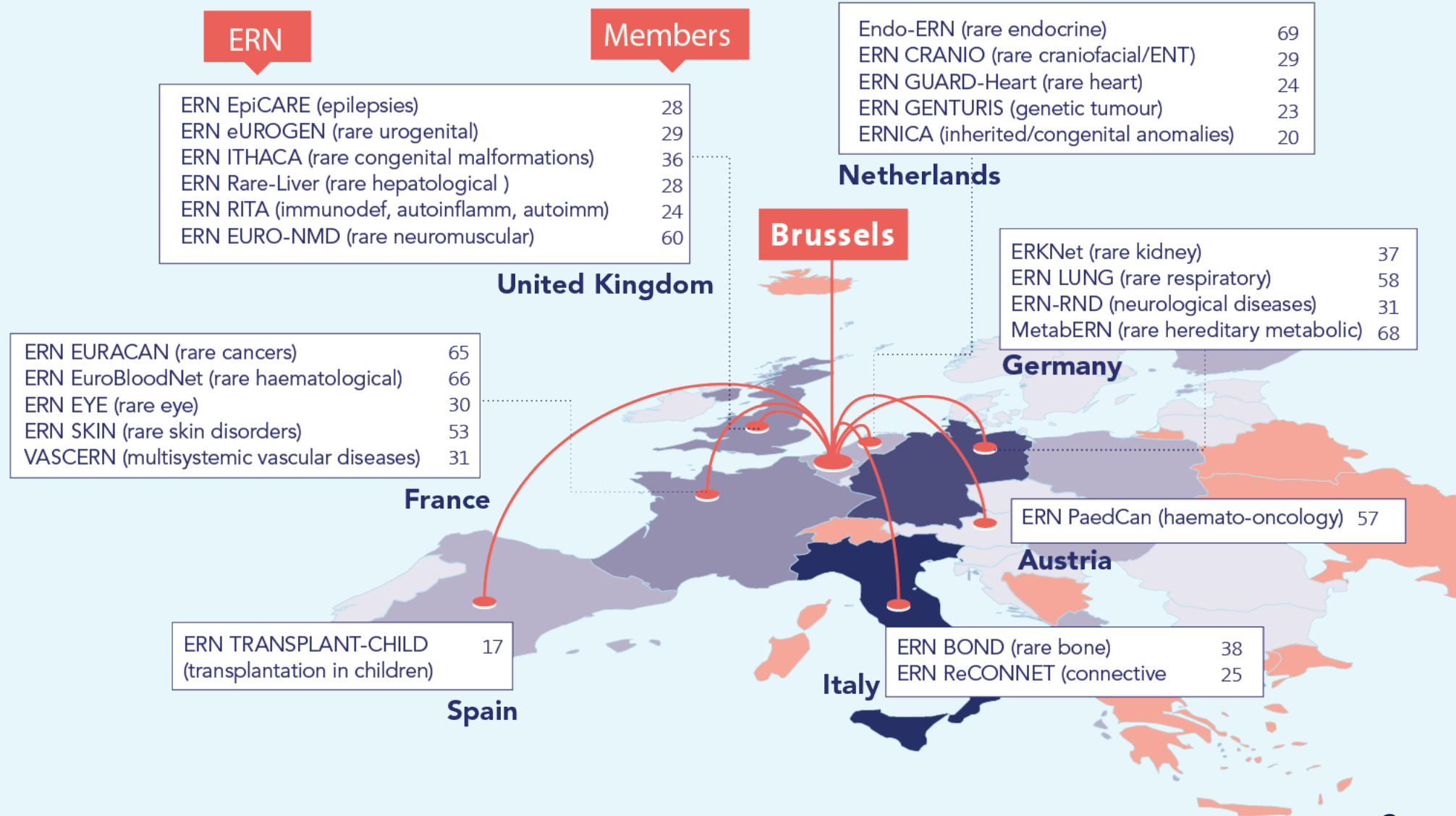
**Plenary Round table IV.
"ERNs' Main challenges for the future"**

**Ernst Kuipers
CEO Erasmus MC
November 22, 2018**

6000 - 8000 RARE DISEASES AFFECTING 30,000,000 IN THE EU



STRATEGIC ALLIANCE ON RARE DISEASES



Numbers of members connected to ERN per country

- Over 50
- Over 40
- Over 30
- Over 20
- Over 10
- Less than 10

CHALLENGES

- Inclusion of centers of expertise on specific diseases that are not yet incorporated within an ERN.
- Inclusion of eligible centers from Southern Europe as well as Eastern Europe, to enable the ERN's to share expertise and to improve access to care for patients across the Union. *
- Sufficient funding for a sustainable growth and development of the ERN's.

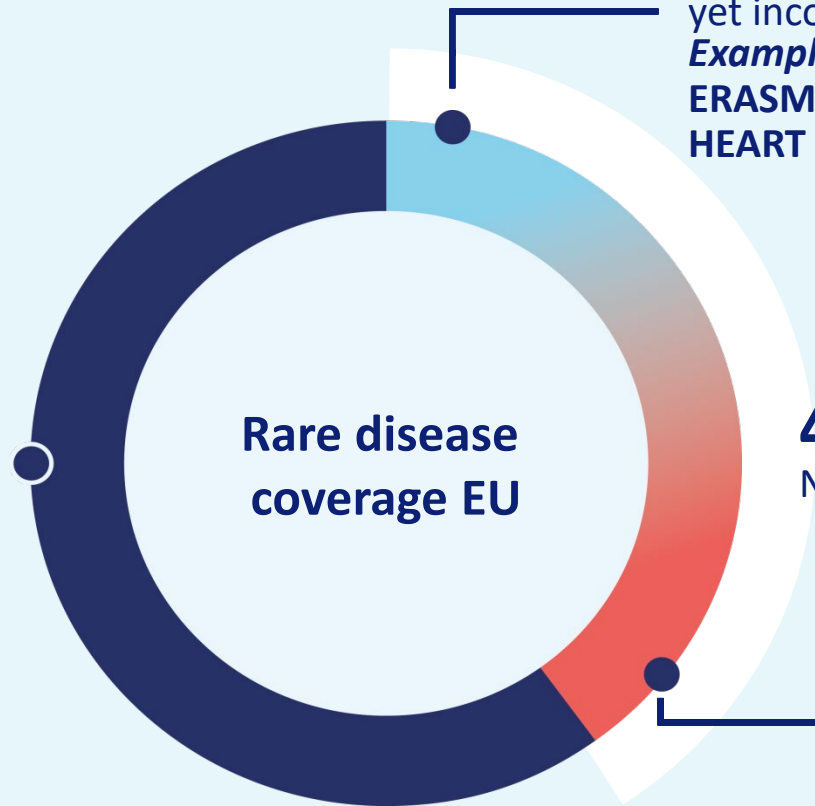
60%
Diseases covered by ERNs

Rare disease
coverage EU

Eligible centers of expertise which are not yet incorporated within an ERN
Example:
ERASMUS MC CENTER FOR CONGENITAL HEART DISEASES BY ERN GUARD- HEART

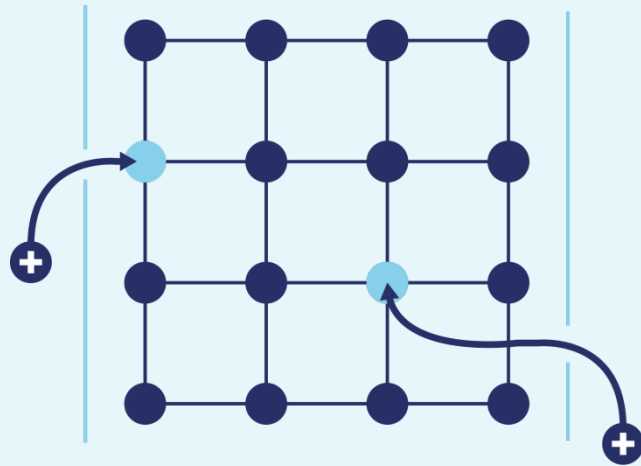
40%
Not yet covered by ERNs

Non-fitting diseases in current ERN landscape
Example:
ERASMUS MC CENTER FOR PREGNANCY INDUCED DISEASES

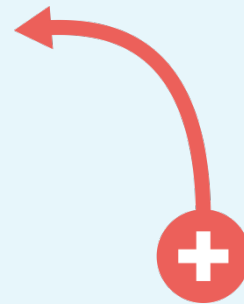


* NB for the support of this initiative, EU structural and investment funds are available [European Structural and Investment Funds](#)

ENLARGEMENT OF THE ERNS (model and procedures)



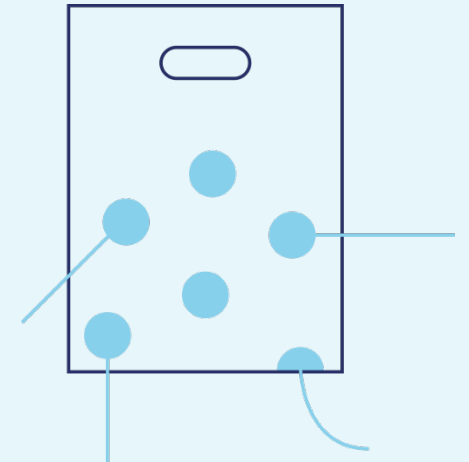
A few **key-players** are **missing**. These might be essential for a good coverage of the network and should be **allowed in as full member**.



A strategy for **connecting eligible centers** of expertise, coming **from countries** that are **already represented** in a network **or** from countries that are **still not represented**.



The **criteria** for new members are to be defined **by the individual ERNs**, not by a one size fits all model.



A strategy for the **inclusion of eligible centers** for rare diseases that are currently **not being covered** by the existing ERNs (**a few new ERNs**).



BUSINESS CONTINUITY

The current annual budget of € 200,000 coming from the EU is **insufficient**



The realistic annual budget around **€ 1 million**

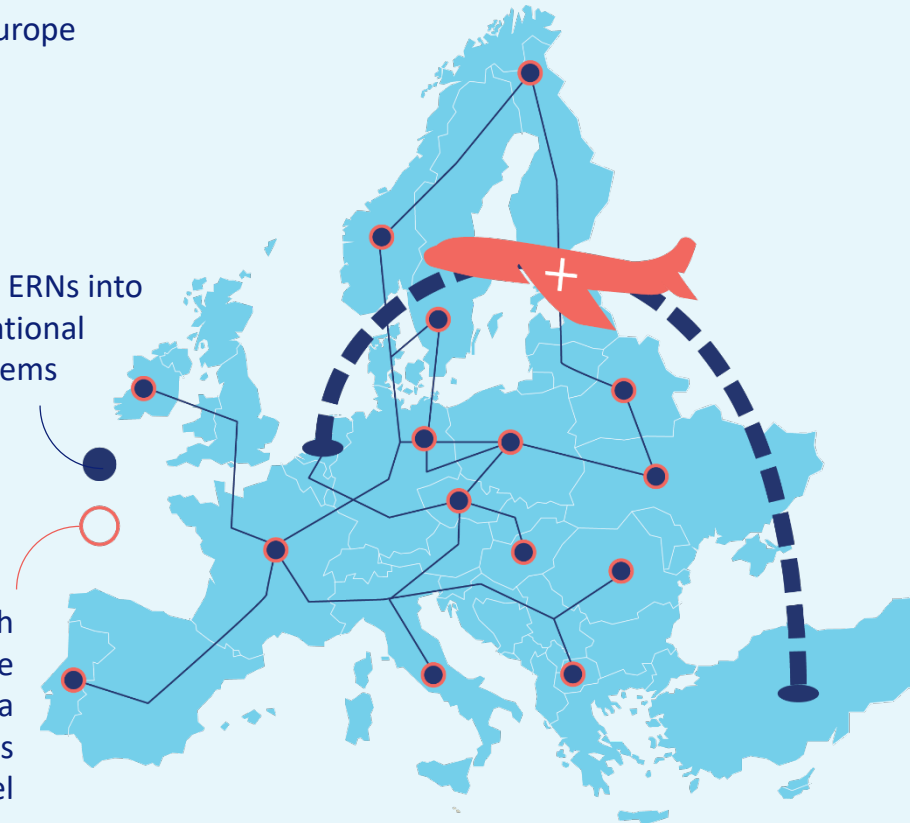


A **5 year budget** instead of an annual budget

The need of significant financial matching by the affiliated center does preclude the active participation of some HCP's from Southern and Eastern Europe

Incorporate the ERNs into the local and national health care systems

Involve the health insurers in the development of a successful business continuity model



It will stimulate an increase in patients travelling for medical care within Europe

SUSTAINABILITY

- A sustainability model for the future financing of the ERNs needs to be defined, and should consider the role of participating HCPs and member states as well as health insurers.
- Leadership, credibility, multidisciplinary and inclusiveness, capacity, links and collaborations are key for further development of the networks.

