



EUROPEAN REFERENCE NETWORKS

**Short Overview of the long winding road
to the current position and future challenges**

Yann Le Cam, Chief Executive Officer

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Time

- **2004**
- **2006 & 2007**
- **2008 & 2009**
- **2011**
- **2014**
- **2015**
- **2019**
- **2025**



Get ready now!

- First Call for Application ERN is in December 2015
- Clinical leaders & patient advocates need to be ready
- Member states need to be ready
- European Commission need to be ready



European Reference Networks

- A critical mass of patients, experts, data and shared tools made possible through European networking
- An **opportunity** for better offering of healthcare to improve access to quality and timely diagnosis and care, to increase quality of life and survival
- An **opportunity** to reduce inequalities of access and quality across Europe
- ERNs are a milestone for RDs, EURORDIS and all RD patient advocacy groups
- ERNs are the embryo of future European healthcare

European Reference Networks

- The challenge is to be « real »
 - How to make sure they are clinically relevant for doctors and patients?
 - How to make it improve patient health and not just connect?
 - How to articulate these ERN with national policy, organisation and choices?
 - How to make sure all rare diseases are covered?
 - Is there something to gain for existing European networks?
 - Where is the money to support these activities?



Work in Progress and a Co-construction

- There is the facts
 - There is what we know and understand
 - There is what we want
 - There is what we don't know
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- ERNs are new to everyone: Commission, Member states, clinicians, patients, payers
 - Together we can have an impact. With PACE-ERN. With an organised diversity and unity.



Patients Health Outcomes

- We don't want ERNs just to connect the « pipes » of the national healthcare systems
- We want to ERNs which improve patients health outcomes: measurable, comparable across Europe
- Medical practices and data are central



Grouping of rare diseases

- ERNs = RDs + non RDs (complex, high cost)
- Not 5 000 ERNs. Not 500 ERNs. Not even 50 ERNs.
- Maximum 20 to 30 ERNs
- RDs as a whole
- All RDs
- All countries
- All People Living With a Rare Disease
- « Every Patient With a Rare Disease has a home »



A RD ERN is a group of clinical networks

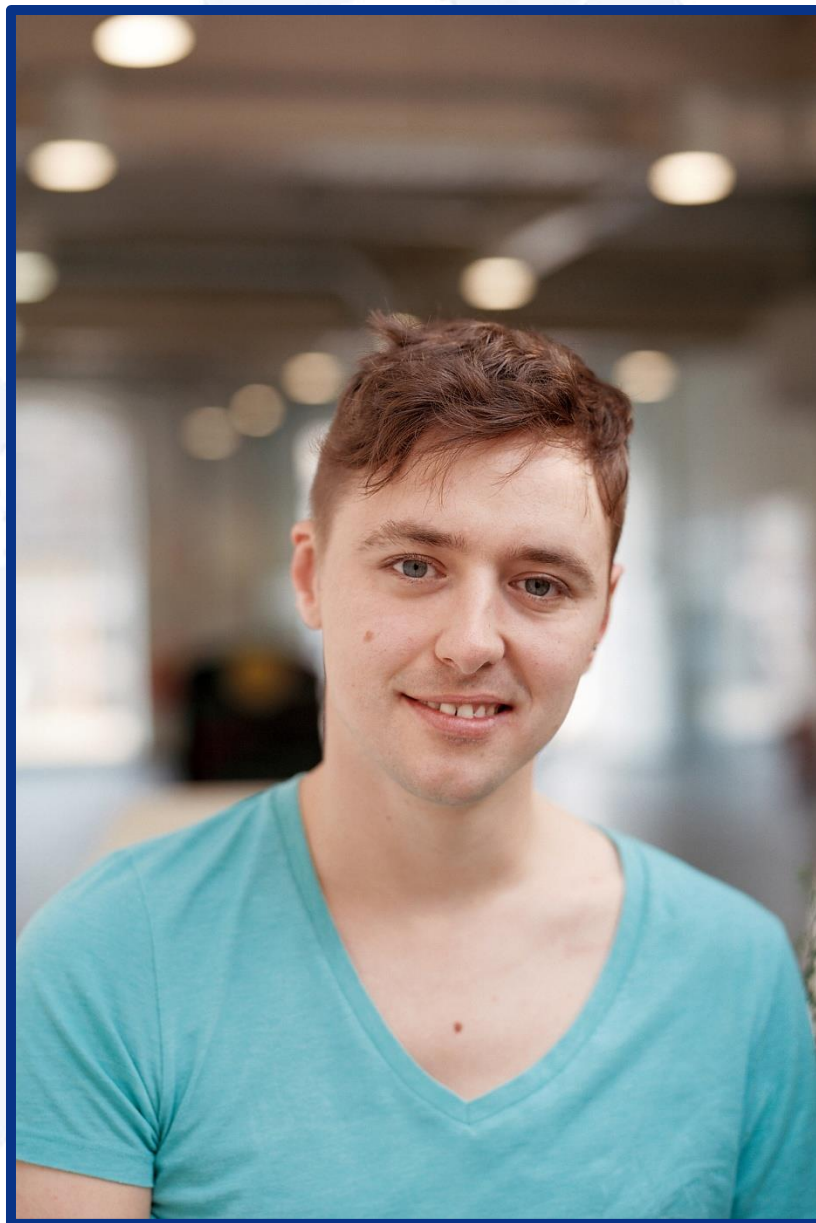
- One **Operational network**
- Several **Clinical networks**

relevant to doctors and patients



Progressive

- Pragmatism! A dynamic process
- The design of the 20-25 ERN is top to bottom
- The construction of the clinical networks is bottom up
- Start with existing or mature networks
- But within a well designed and structured approach
- Progressive larger scope of rare diseases
- Progressive wider geographic coverage
- Progressive extension of activities and deeper activities



Patient engagement

- Engagement in the governance of ERN for RDs (eg: defining priorities; progressiveness of coverage; ; identification of centres and healthcare providers)
- Engagement in activities of ERN (eg: communication; practices of diagnostic and care; registries; clinical trials)
- Engagement in Centres of Expertise



Implications for EURORDIS & members

- Organise ourselves now for the ERN applications and for the long term
- Organise grouping of members for democratic representation in ERN, relevant collective work, proper planning and involvement
- Organise to build the capacities of all patient advocates concerned through networking, exchange of information, learning from each other, staff support



Implication for patient advocates

- Understanding the policy, the process, the criteria
- Lots of reading and appropriation
- Liaise with your clinical leaders (a European Workshop for clinical leaders in RDs will be organised in 1-2 July by CEG RD & Joint Action)
- Liaise between national patient groups and your European network or federation to push up the Centres of Excellence or Health Care Providers
- Be ready for new tasks (& time) linked to ERNs



Now.....

- We know it will take 10 years
- We know there are uncertainties and risks
- We know it will be challenging
- Will our collective intelligence, vision, enthusiasm be sufficient to reduce these uncertainties? Mitigate risks with the gains? Overcome the challenges ahead?
- We have been at the origin and at the centre of this policy, we are striving to continue to be. Can we make ERN patient centric?