

Implementation of European Reference Networks

**Fifth meeting of the
ERN Board of Member States
7 March 2016**



***DG SANTE
Directorate B
European Commission***

✓ **Health Programme – Work Programme 2016:**

- Approved ERNs (eligibility criteria)
 - **Call for Grants** jointly with the ERN Call for interest
 - **Patient registries projects**
- For **technical assistance** for the assessment of applications
- **3rd ERN Conference** (February 2017) Kick off meeting approved ERN

ERN Approval

1. Call
2. Assessment for ERN
3. Positive assessment
4. Approval of the Board

October 2016?

5. ERN established

November 2016

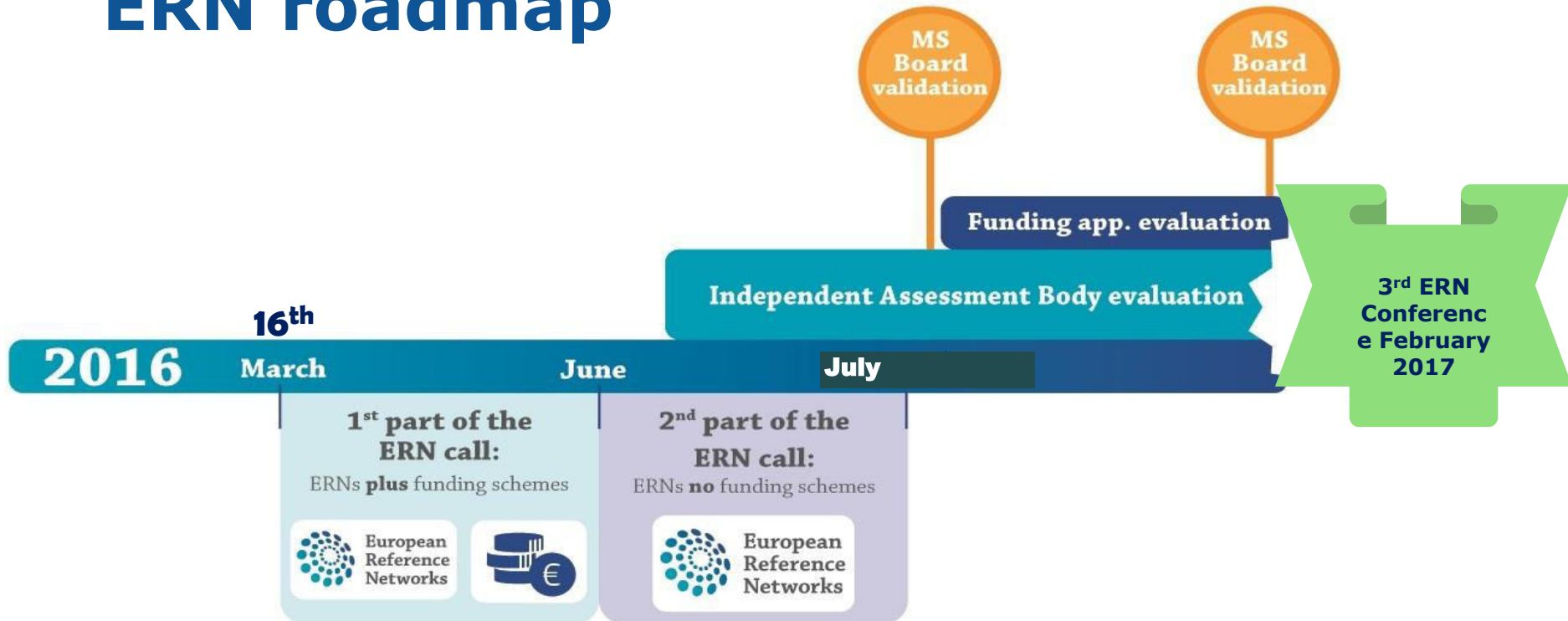
Grant

1. Eligible for funding **November 2016**
2. Evaluation of the grant proposal
3. Positive evaluation Framework - Partnership Agreement (FPA)
4. Eligible for Specific Grant Agreement (SGA) **February 2017**

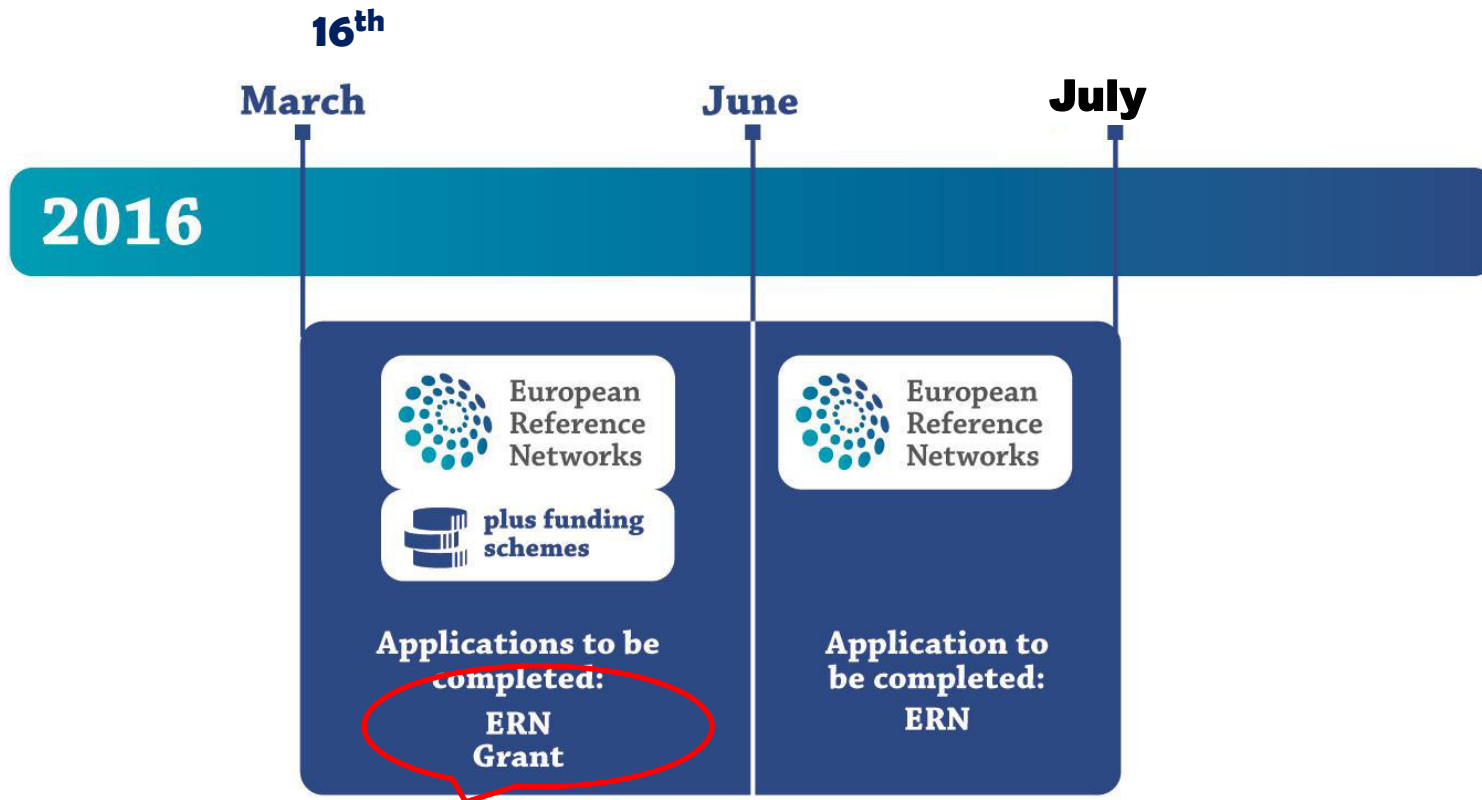


European
Commission

ERN roadmap



The call for ERNs: a two steps process



CHAFEA presentation

The call for ERNs



Actors involved

1. *Network coordinator*
2. *Healthcare Providers (HCPs) belonging to the ERN candidate*

Application

3 applications (1 for ERN & 2 for the grant - FPA and SGA):

ERN application form

- **1 ERN** application & ERN Self-assessment
- **N Members**
 - Members application forms
 - Members self-assessments
 - Member State endorsement

Grant application

FPA and SGA

Communication & awareness activities



European Commission

Info Day

Third European Union Action Programme in the field of Health - National Focal Points Meeting **18th March**

ERN Info day
7th April



European Reference Networks

Share your expertise for the best healthcare

European Reference Networks Share, Care, Cure.

Anna Carta
DG SANTE
Directorate B
European Commission

European Reference Networks

Directive of patients' rights in cross-border healthcare

10.03.2016

Enrique Terol
DG SANTE
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European Commission



Tentative list of potential ERN candidates



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Groups of diseases	broad scope 13	Advanced draft proposal 12	Name of the project Current/future
Rare auto-immune and auto inflammatory diseases	X	X	RITA
Rare Bone Diseases	X	X	Rare Bone Diseases Network
Rare Cancers and Tumours	X	X	Expornet Paediatric
Rare Cancers and Tumours	??		Adult (12 networks?)
Rare cardiac diseases			
Rare connective tissue and musculoskeletal diseases			
Rare malformations and developmental anomalies and rare intellectual disabilities	X	X	Rare malformations and developmental anomalies and rare intellectual disabilities
Rare endocrine diseases			Rare diabetes in children
Rare endocrine diseases			Neuroendocrine tumours/diseases
Rare eye diseases			
Rare gastrointestinal diseases			
Rare gynaecological and obstetric diseases			
Rare haematological diseases	X		Onco-hematologic
Rare haematological diseases	X	X	Rare anemias
Rare head and neck diseases			
Rare hepatic diseases	X (ped)	X	Rare hepatic diseases and transplantation
Rare hereditary metabolic disorders	X	X	MetabERN
Rare multi-systemic vascular diseases			
Rare neurological diseases		X	e-pilepsy
Rare neurological diseases	X		
Rare neuromuscular diseases	X	X	Rare neuromuscular diseases
Rare pulmonary diseases	X	X	
Rare pulmonary diseases			ECMO
Rare renal diseases			
Rare skin disorders	X	X	Rare skin disorders
Rare urogenital diseases	X	X	Rare urogenital diseases

...food for thoughts



- ✓ The **strategic paper of the Board** sent a **strong message** and together with the opinion of the Rare Diseases expert group is already having an **impact on the potential candidates**.
- ✓ A **number of groups** are already **embracing this integrative approach** and are trying to prepare joint networks proposals of previously fragmented projects. That is the case by instance of neurology, haematology, uro-gynaecology, paediatric rare cancers, neuromuscular, autoimmune and auto inflammatory diseases, dermatology etc.
- ✓ Of course, we **cannot prevent that narrower proposals are presented** (this is a legal right) but this is precisely the **very important role of the Board: to steer the process** and take strategic decisions when it would come to the approval stage.
- ✓ There is a **high variability in this exercise** and it seems very difficult to express clear priority therefore it is **up to the board to decide on this matter**