



# ERNs

## Lessons learned: Coordinators' perspective Virtual Meeting 21<sup>st</sup> October 2021



**Hélène Dollfus**  
**On behalf of ERN- Coordinators Group ERN-CG**  
ERN-EYE coordinator  
Strasbourg University Hospital  
France



# The life of ERNs

**7000** LOW PREVALENCE & COMPLEXE & RARE DISEASES – **30 M** EU patients

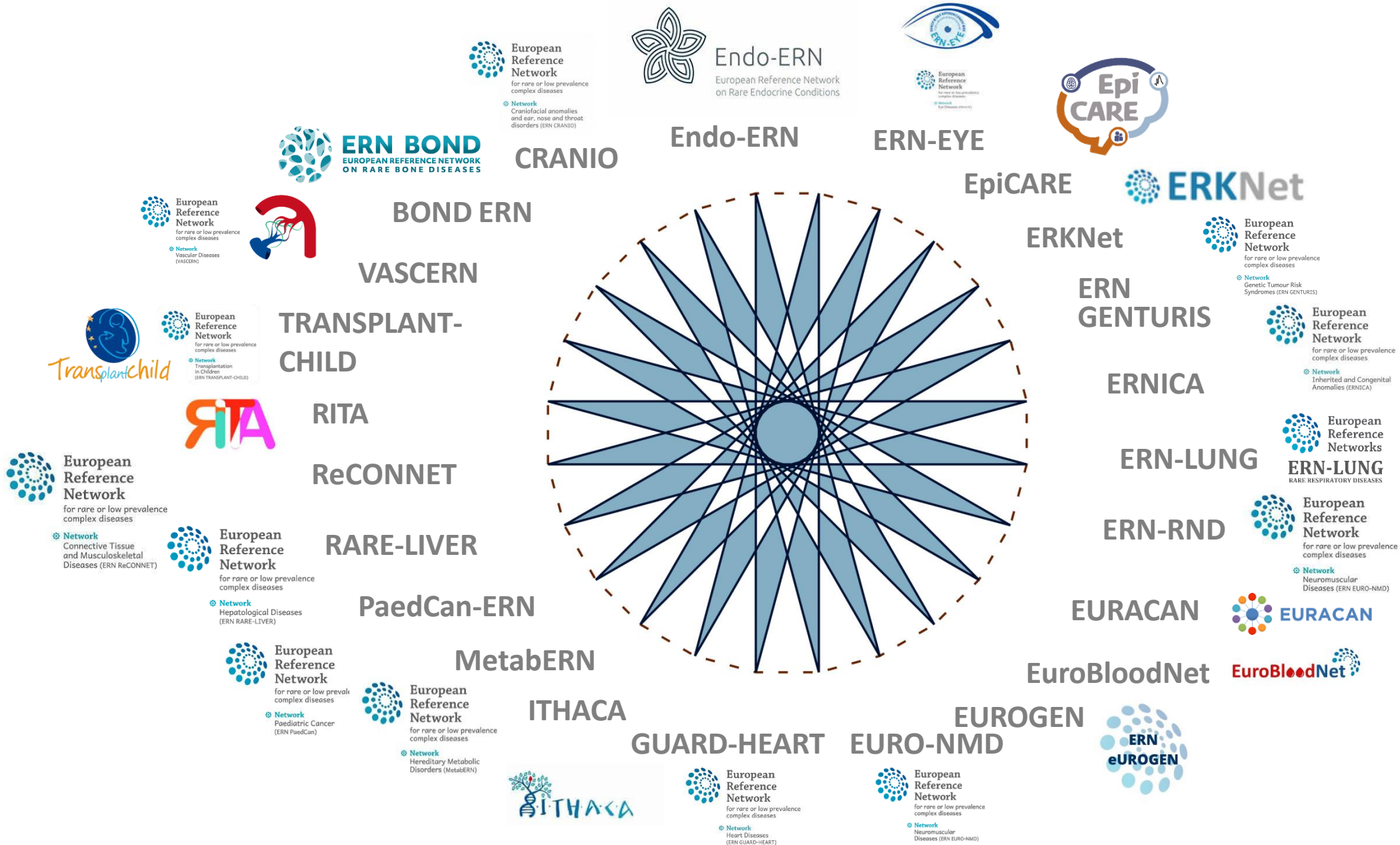
Bring expertise and excellence to all EU citizens

- A long process since **2004** with the first Rare Disease Task Force
- Council Recommendation in **2009**
- Cross Border Health DIRECTIVE **2011/24/EU**
- **2015** implementation by the commission
- **2017** launch of 24 ERNS **for 5 years**

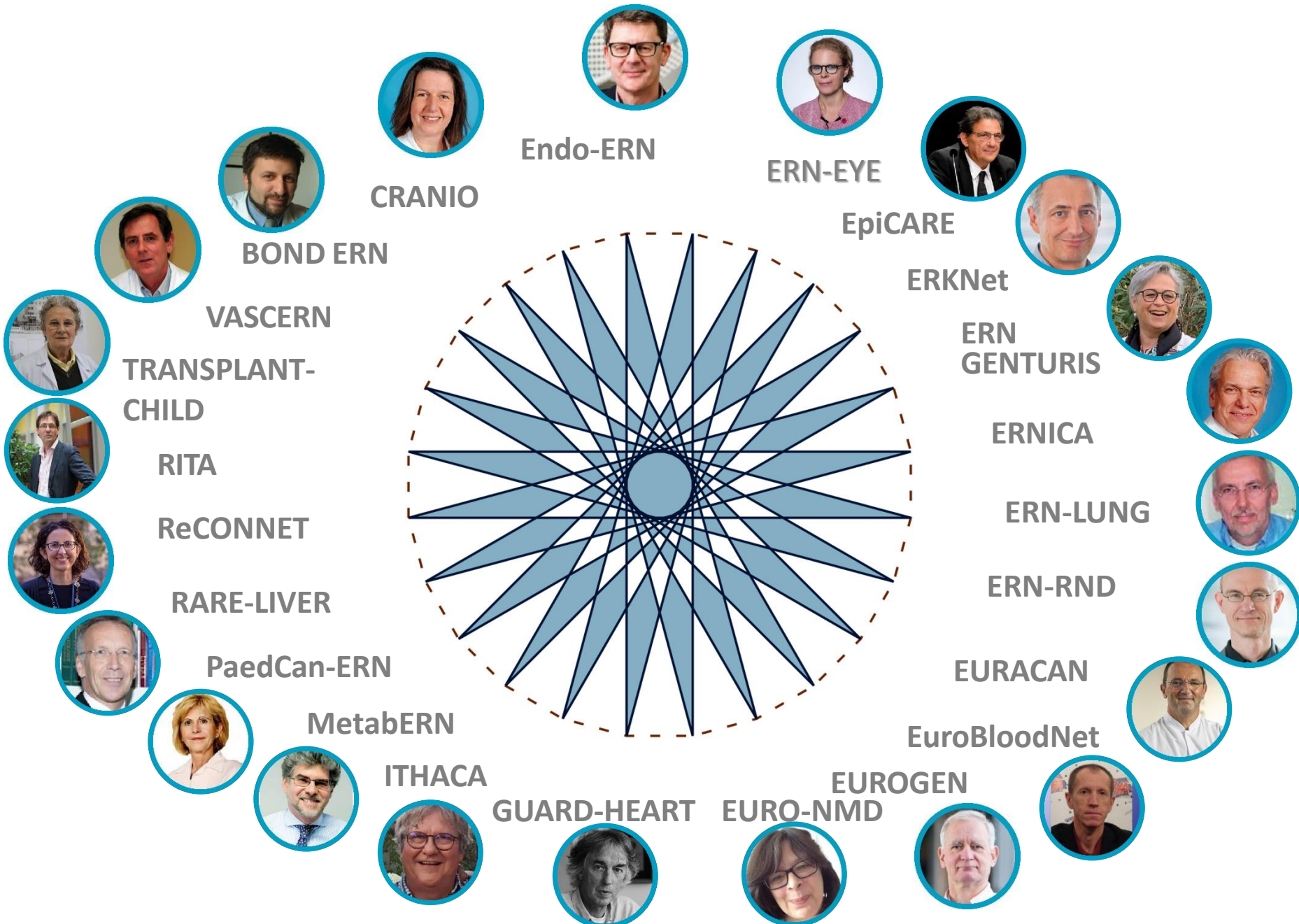


# 24 ERNs – Thematic networks

over 900 healthcare units



# 24 Coordinators



# The ERN Coodinators Group

2017/2018



**Maurizio Scarpa**  
MetabERN,  
Udine University  
Hospital, Italy

2018/2019



**Franz Schaefer**  
ERKnet  
Heidelberg University  
Hospital, Germany

2019/2020



**Irene Mathijssen**  
ERN Cranio  
Erasmus MC, Rotterdam,  
Netherlands

2020/2021



**Nicoline Hoogerbrugge**  
ERN Genturis  
Radboud University  
Medical Center,  
Nijmegen, Netherlands

2021/2022



**H el ene Dollfus**  
ERN-EYE  
CHRU Strasbourg,  
France

2022/2023



**Alexis Arzimanoglou**  
ERN EpiCARE  
Lyon Hospital, France

The coordinator HCP is administrates the ERN  
Coordinators are in charge of piloting at the fonctionnal level the ERNs  
In close collaboration with all stake hodlers of the **ERN ECOSYSTEM**

European  
Commission



Board of Member States  
BoMS



Patient  
representatives



ePAGs

All  
other  
stakehodlers

# ERN's at a glance

- > 900 Health Care Providers accross Europe : in each MS = 2 to 188 HCPs
- In 2017 HCPs in an ERN : from **17 to 78** (~ 25) and **~X2 in 2022**
- The 24 ERNs have different « natural histories »
- The 24 ERNs cover huge medical fields
- The 24 ERNs are heterogeneous: diseases, patient needs, access to therapy, ....



- BUT we have the same GOALS = IMPROVE CARE for Rare Diseases  
AND we allready collaborate closely in multi ERN activities cf ERICA  
& collectively can react rapidly cf pandemic COVID statements & vaccination indications



- Coordinators run CENTRAL management OFFICE from his HCP , Working Groups -  
Goverance board & Networking meetings & MISSIONS

# ERNs missions

« *Knowledge travels and not the patient* » & « *Leaving no one behind* »

Triple obligation :

1. Highly specialized Healthcare
2. Research
3. Education



- CASE PATIENT MANAGEMENT SYSTEM => CPMS
- RARE DISEASE DATA collection: REGISTRIES ( > 30)
- PROVIDE BEST PRACTICES - Know How's- GUIDELINES
- TRAINING – EDUCATION
- IMPULSE RESEARCH
- BOOST RESEARCH for THERAPY – CLINICAL TRIALS

# ERNs missions

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=>

PRODUCTIONS AT ALL LEVELS FOR ALL ERNs

European Reference Networks eUROGEN  
European Reference Networks ERNICA

### ERN eUROGEN Webinars

**Syndromic forms of caudal malformations**  
presented by  
Prof Sabine Sarnacki & Dr Célia Crétolle  
Tuesday 20 April, 18:00-19:00 CEST

European Pediatric Surgeons' Association  
Co-financed by the Connecting Europe Facility of the European Union

European Reference Network  
EUROPEAN REFERENCE NETWORK ON RARE BONE DISEASES

### WEBINAR

**Gender issues in COVID-19 pandemia**  
Tuesday June 22nd 2021  
at 11:00 – 12:00 CEST

Speaker:  
Prof. Maria Luisa Brandi

European Reference Network  
for rare or low prevalence complex diseases  
Skeletal and Congenital Anomalies (ERNICA)

### CAN EAT

Care And Nutrition in Esophageal Atresia  
An ERNICA animation for parents and families

L'Atresie de l'oesophage est une malformation congenitale rare qui se caracterise par l'absence d'une partie de

### JOIN OUR NEXT WEBINAR

**Marfan Syndrome: An Update**  
Joint webinar - ERN-EYE & VASCERN  
APRIL 27<sup>th</sup>, 2021 6:00 PM CEST

SPEAKER  
Pr Julie De Backer

SPEAKER  
Pr Bart P Leroy

SPEAKER  
Dr Elke O KREPS

### Diagnostic Procedures

#### Patient Case

You are a consultant epileptologist, a member of a reference for rare and complex childhood epilepsies. You receive Jules, 18 months old, and his mother. He is referred to you for assessment, confirmation of diagnosis and advice on optimal treatment of



# ERNs & PARTNERS

« *Knowledge travels and not the patient* »

& « *Leaving no one behind* »

=> RARE DISEASE ECOSYSTEM INTEGRATED ACTIONS

- CASE PATIENT MANAGEMENT SYSTEM **CPMS**
- RARE DISEASE DATA collection: **REGISTRIES**
- PROVIDE BEST PRACTICES –Know How’s- **GUIDELINES**
- TRAINING – **EDUCATION**
- IMPULSE **RESEARCH**
- BOOST RESEARCH for THERAPY – **CLINICAL TRIALS**

orphanet

EUROPEAN JOINT PROGRAMME  
**RARE DISEASES**

**ERICA**  
European Rare Disease Research  
Coordination and Support Action

conect  
**4children**  
COLLABORATIVE NETWORK FOR EUROPEAN  
CLINICAL TRIALS FOR CHILDREN

**IRDIRC**  
INTERNATIONAL  
RARE DISEASES RESEARCH  
CONSORTIUM

**eatris**  
European infrastructure  
for translational medicine

**BBMRI**  
Biobanking and  
Biomolecular  
Resources Research  
Infrastructure

**ECRIN**  
EUROPEAN CLINICAL RESEARCH  
INFRASTRUCTURE NETWORK



« *Knowledge travels and not the patient* »

& « *Leaving no one behind* »

=> INTEGRATED ACTIONS FITTING EU MAIN HEALTH PROGRAMS

- CASE PATIENT MANAGEMENT SYSTEM **CPMS**
- RARE DISEASE DATA collection: **REGISTRIES**
- PROVIDE BEST PRACTICES –Know How’s- **GUIDELINES**
- TRAINING – **EDUCATION**
- IMPULSE **RESEARCH**
- BOOST RESEARCH for THERAPY – access to orphan medications & **CLINICAL TRIALS**

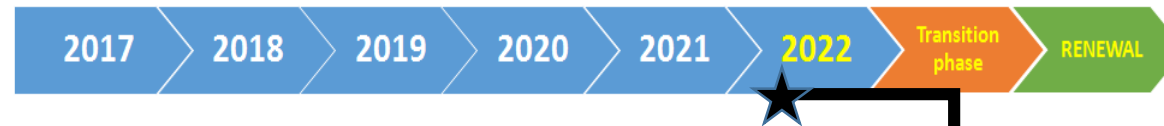


EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

# ERNs: past, current & future Challenges

- **BREXIT** => coordination changes + losing UK members
  - **ERN new membership**: on going process until end of 2021 **X2 in size**
- => Better coverage – reach out better central and Eastern EU
- **Management** : partners engagement => each HCP as a member supports the ERN activities (but needs in return added value )
  - **Monitoring** : needs to be continuous & feasible
  - **National Integration of ERNs**: integration into the Member State Healthcare system is complex & improve patient pathways accross the EU
  - **Data policies - local & national regulations**: registries implementation & need for local resources
  - **Collaboration with industry** : registries & therapy developement
  - **Boosting RD research** at the ERN level

# ERNs challenges : BUDGET



## Initial 5 years funded by GRANTS

NB:

CO-FUNDING by the coordination HCP 40%

- **GENERAL GRANT**

3rd Health program –last multiannual plan  
FPA5 yrs, 3 SGA (CHAFEA-HADEA)

- **SPECIFIC GRANTS**

➤ CPMS helpdesk :

➤ CEF Connecting Europe Facility (INEA)

➤ REGISTRIES: 3rd Health program

3 yrs SGA (CHAFEA-HADEA)

## From March 2022

End of the 5 first years period

Transition zone

Coïncides with EU4Health budget

**End of the Co-funding**

Question on the sustainability for  
the renewal of ERNs

# ERNs Challenges: **BUDGET**

- From 2017 -2022 :

ERN BUDGET is for coordination => **270 000 euros / year** (with co-funding)



[March 2022: URGENCY to secure the Human Ressources because of temporay contracts]

- The ERN-CG has estimated the **real cost of a generic ERN** :taking into account the expanded managing & monitoring activities, deployment of registries (funding partner HCPS) and continuity with simplified CPMS, education, guidelines ect ...

- 2018 ERN-CG estimation => 900k€ per year as a minimum

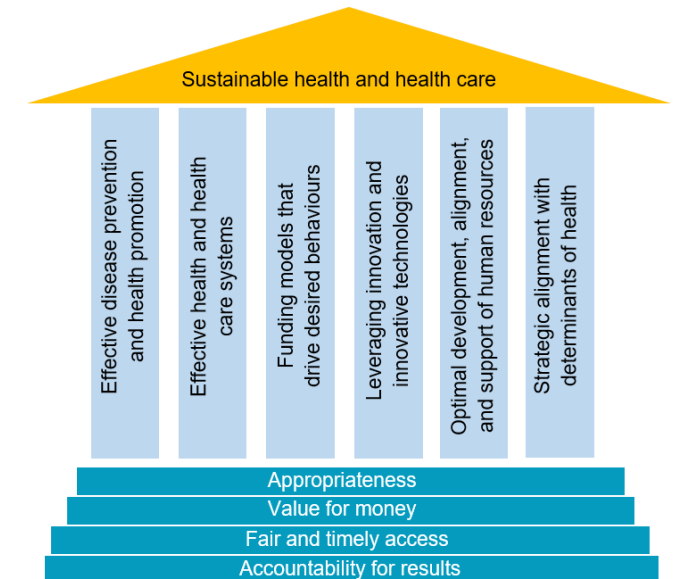
- 2021 ERN-CG estimation => **1M€ per year as a minimum**

⇒ EU4Health BUDGETS are currently in decision process ( 2022 + next)

⇒ **Plea from the ERN-CG for support in obtaining reinforced & realistic budgets**

# ERNs : heading for maturation ....

- ERNs are the first Healthcare network labelled by the EC
- An paradigm of solidarity & cross border cooperation & reduce inequalities
- Patients are strongly engaged & full partners
- Since 2017 many actions have been achieved and are visible
- **BUT WE CAN STILL DO BETTER**
  - National integration in MS systems
  - Stimulate all members to participate activities & find added value
  - Reinforce the networking activities with new members
  - Data capture, use and re-use – INTEROPERABILTY
  - Guideline and education material production
  - Communication
  - Ect ....
- LAST BUT NOT LEAST we need : **ad hoc BUDGETS**





## 5 key points



- **January 2022** : ERNs will double in number of members (X2)
- **March 2022**: end of the first 5 years general GRANT
- **From March 2022** : a reinforced budget is needed 1Meuros/year ( X5)
- **Immediate priority** : National integration in healthcare system & HCPs
- **Immediate priority** : EU Data Health space full integration at all levels

# Thank you!

Contact to the ERN-CG 2021 : [ERN-CG2021@chru-strasbourg.fr](mailto:ERN-CG2021@chru-strasbourg.fr)



European  
Reference  
Networks

ERN Coordinators Group







**ERN BOND**

Luca Sangiorgi,  
Istituto Ortopedico Rizzoli, Bologna, Italy



**ERNICA**

René Wijnen  
Erasmus MC, Rotterdam, Netherlands



**ERN CRANIO**

Irene Mathijssen  
Erasmus MC, Rotterdam, Netherlands



**ERN LUNG**

Thomas Wagner  
University Frankfurt, Germany



**Endo-ERN**

Alberto Pereira  
University Medical Center Leiden , Netherlands



**ERN Skin**

Christine Bodemer  
Necker-Enfants Malades Hospital



**ERN EpiCARE**

Alexis Arzimanoglou,  
Lyon Hospital, France



**EURACAN**

Jean-Yves Blay  
Lyon Hospital, France



**ERKNet**

Franz Schaefer  
Heidelberg University Hospital, Germany



**EurobloodNet**

Pierre Fenoux  
St-Louis Hospital, Paris, France



**ERN-RND**

Holm Graessner  
Tübingen University Hospital, Germany



**ERN eUROGEN**

Wout Feitz  
Radboud University Medical Center



**ERN-EYE**

Hélène Dollfus  
CHRU Strasbourg, France



**ERN-PaedCan**

Ruth Ladenstein  
St. Anna Children's Cancer Research Institute (CCRI), Vienna  
Austria



**ERN Genturis**

Nicoline Hoogerbrugge  
Radboud University Medical Center,  
Nijmegen, Netherlands



**ERN RARE- LIVER**

Ansgar Lohse  
Universitätsklinikum Hamburg-Eppendorf (UKE), Germany



**ERN GUARD- HEART**

Arthur Wilde  
Amsterdam UMC , Netherlands



**ERN reCONNET**

Marta Mosca  
Azienda Ospedaliero Universitaria Pisana, Pisa, Italy



**ERN ITHACA**

Alain Verloes  
APHP Paris Nord, France



**ERN RITA**

Nico Martinus Wulffraat  
University Medical Center, Utrecht



**MetabERN**

Maurizio Scarpa  
Udine University Hospital, Italy



**ERN TRANSPLANT-  
CHILD**

Paloma Jara Vega  
Hospital Universitario La Paz, Spain



**ERN EURO-NMD**

Teresinha Evangelista  
GH Pitié-Salpêtrière, Paris



**VASCERN**

Guillaume Jondeau  
Bichat Hospital, Paris