



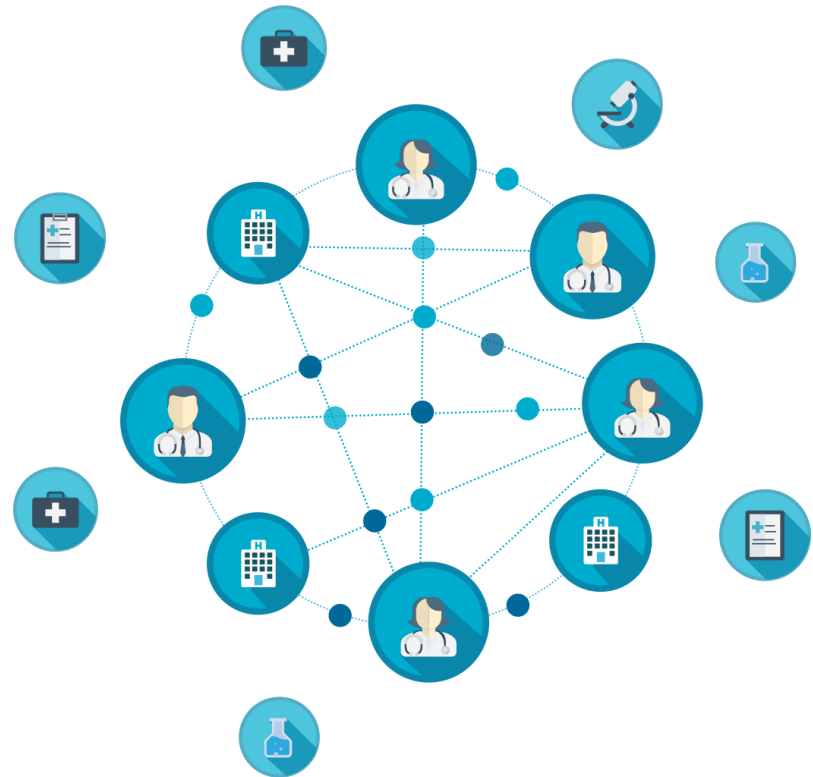
ERN Communication

MEETING NCP CBHC – 05/05/2017

WHY?

Main ambitions

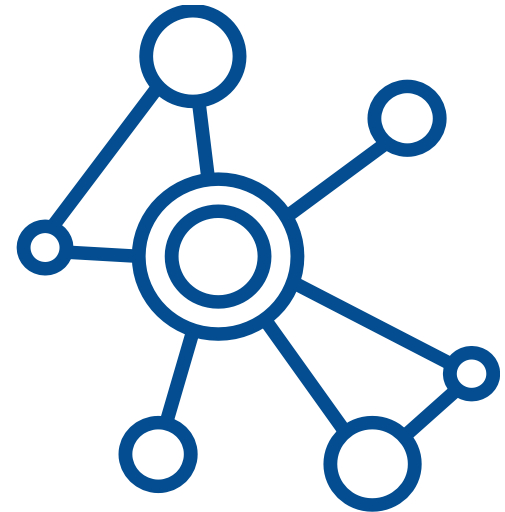
- **Involve (future) partners**
- **Inform beneficiaries**
- **Manage expectations**
- **Show added value EU cooperation**



WHAT?

Key messages

- **What ERNs are**
- **How ERNs work for HCP**
- **How ERNs work for patients**
- **Concrete results**



TO WHOM?

Priority target audiences:

- **Health care providers and health researchers in Europe (non-members ERNs)**
- **Patients organisations**
- **Media (at EU level and in the Member States)**



WHO?

Lead:

- **ERN Members**
- **National health authorities**

Support:

- **European Commission – DG SANTE**
- **European Commission Representations**



HOW?

Commission actions:

- **Press communication (Leuven, Vilnius)**
- **Flyer (all languages)**
- **Information brochure (EN; more languages soon)**
- **Social media campaign (#ernEU)**
- **Web section <http://ec.europa.eu/health/ern>**
- **Videos (animation clip; in-depth reportages to follow)**

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES
Share. Care. Cure.

18/02 2017 PROGRAMME MEDIA SEMINAR
UNIVERSITY HOSPITAL LEUVEN

10:00 - 11:15 WELCOME AND INTRODUCTIONS
Prof Marc Decramer, CEO, University Hospital Leuven
Xavier Prats Monné, Director-General, Health and Food Safety, European Commission
Yann Le Cam, CEO of EURORDIS

11:15 - 11:30 COFFEE BREAK

11:30 - 12:15 CASE STUDY:
ERN ON RARE MULTISYSTEMIC VASCULAR DISEASES
Prof Guillaume Jondeau, Hôpital Bichat Paris, ERN Coordinator
Dr Sarah Thomis, University Hospital Leuven
Patient testimony by Nele Verhaegen

12:15 - 12:45 PRESS STATEMENTS
Vytenis Andriukaitis, European Commissioner for Health and Food Safety
Maggye De Block, Federal Minister for Social Affairs and Health

12:45 - 13:45 BUFFET LUNCH

13:45 - 14:30 CASE STUDY: ERN ON PAEDIATRIC CANCER
Prof Ruth Ladenstein, St. Anna Kinderspital Vienna, ERN coordinator
Prof Arne Uytendaele, University Hospital Leuven
Patient testimony by Zoran Velickovic

14:30 - 14:45 CONCLUSIONS
Xavier Prats Monné, Director-General, Health and Food Safety, European Commission



ec.europa.eu/health/ern
@EU_Health
#ernEU



EUROPEAN COMMISSION
PRESS RELEASE

Brussels, 28 February 2017
European Reference Networks: 900 medical teams to connect across Europe for the benefit of patients

March the newly established European Reference Networks (ERNs) will start their work. ERNs are unique and innovative cross-border cooperation between specialists for the diagnosis and treatment of rare and complex diseases.

Minister for Health: "We must join forces and develop care for our patients suffering with rare diseases. The latest treatments, in this context, we have with the Grand Duchy of Luxembourg, the pharmaceutical industry to keep the prices continue down this path, as by working with the European Reference Networks."

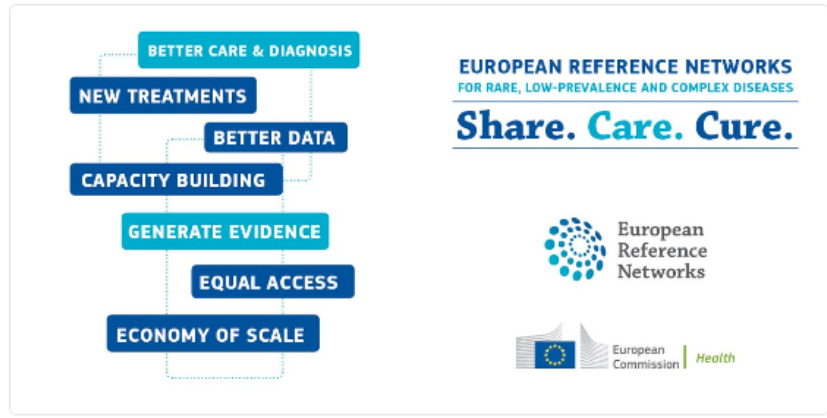
specialised healthcare units from a wide range of issues, from bone and paediatric cancer to on this scale should benefit requiring a particular al domains where the



Volg je nu

European Reference Networks: 900 medical teams to connect across #EU for the benefit of patients #ERNEU #raredisease europa.eu/rk73kX

Vertalen uit het Engels



RETWEETS
23

VIND-IK-LEUKS
18



03:13 - 28 feb. 2017

Rare Diseases Europe, EU_Health, Vytenis Andriukaitis and 2 others

1 23 18

Europos dovana, kuria pasinaudos ir Lietuva: aktualu daugeliui pacientų (6)

Giedrė Armalytė
Sveikatos naujienų redaktorė
2017 m. vasario 28 d. 15:03

Kovo 1 d. Europos medikų ir pacientų bendrija. Po metų derybų pagaliau startuoja Europos referenciniai tinklai. Tikimasi, kad europinio masto bendradarbiavimo galimybės gydytojams ir pacientams bus gerokai išplėtos ir kaupiant žinias apie retų ligų gydymą, aukštos kokybės paslaugas retomis ligomis sergantiems pacientams.



Una red de colaboración europea en enfermedades raras

Nyheter

Nya EU-nätverk ska ge bättre vård

PUBLICERAD 2017-03-01

Den som har en sällsynt sjukdom kan ha svårt att få rätt behandling eftersom det ofta saknas expertkunskap i landet. Nu ska ett EU-initiativ förbättra vården för de 30 miljoner människor i EU som har en ovanlig sjukdom.



Skriv ut | Rätta artikel | Bokmärk

Det finns fler än 6 000 kända sällsynta sjukdomar. En sjukdom räknas som sällsynt om den förekommer hos högst fem per 10 000 människor, enligt EU:s definitioner. I vissa fall har kanske



EL MUNDO

TERVIST24 Tervist24 | UUDISED

HEA UUDIS: haruldaste haiguste diagnoosimise alates homsest lihtsamaks (7)

Silja Paavle, 28. veebruar 2017, 13:30

JAGA LUGU! | LISA TVIIT | Prindi



FT Financial Times was live. 28 februari om 16:02 - On Rare Disease Day, share your questions with the European Commissioner for Health. Vertaling bekijken 91K weergaven

EU_Health  @EU_Health

.@V_Andriukaitis: "Today we are sending a message of integration" #EU #health #raredisease #ERNs - full room in Vilnius at #ERNEU conference



RETWEETS 26 LIKES 22

8:25 AM - 9 Mar 2017



Vytienis Andriukaitis  @V_Andriukaitis Following

We will work hard to ensure that #ERNEU reach their potential, expand, and open up opportunities for more! bit.ly/2IGWe2j



RETWEETS 15 LIKES 10

ERN launch:
 → 127K accounts reached

ERN conference:
 → 80K accounts reached

Promo video (Mar.-Apr.):
 → 490K views

HOW?

Communication toolkit for members and partners:

- **Press material (incl. Q&A)**
- **Logo and visuals**
- **Publications**
- **Social media, web guidelines and online visuals**
- **Videos**

http://ec.europa.eu/health/ern/toolkit_en



<http://ec.europa.eu/avservices/video/player.cfm?sitelang=en&ref=I134312>



European
Reference
Networks

http://ec.europa.eu/health/ern/toolkit_en



@EU_Health
#ernEU