



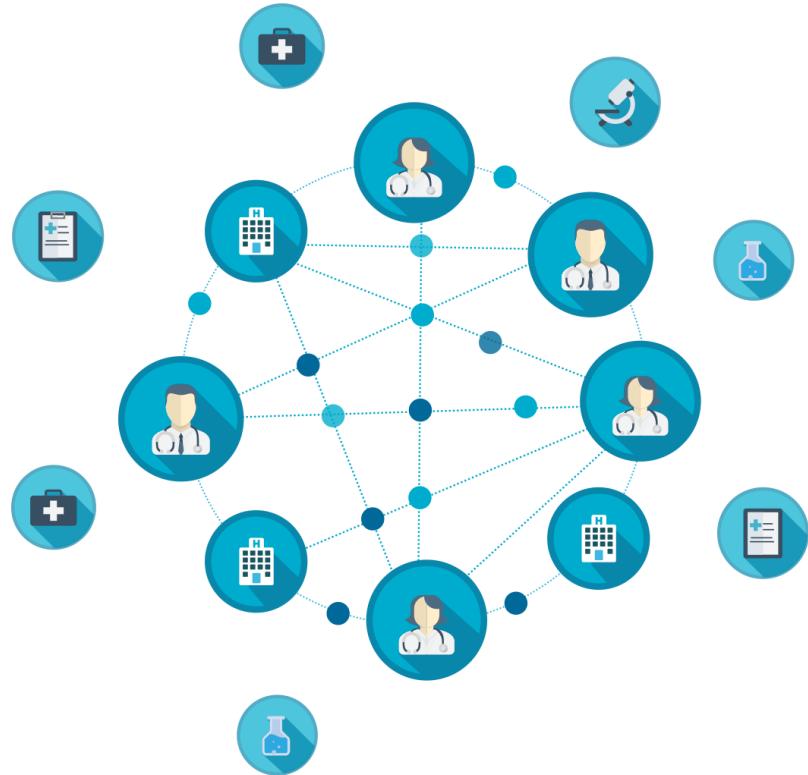
ERN Communication

MEETING NCP CBHC – 05/05/2017

WHY?

Main ambitions

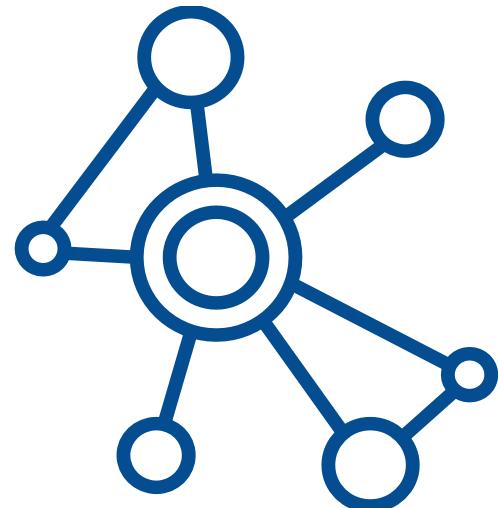
- **Involve (future) partners**
- **Inform beneficiaries**
- **Manage expectations**
- **Show added value**
EU cooperation



WHAT?

Key messages

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

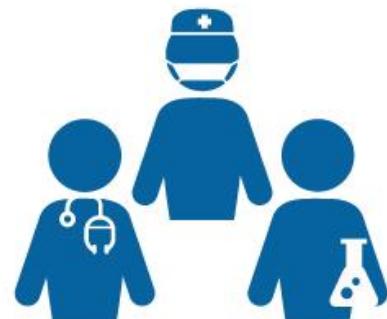




TO WHOM?

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:

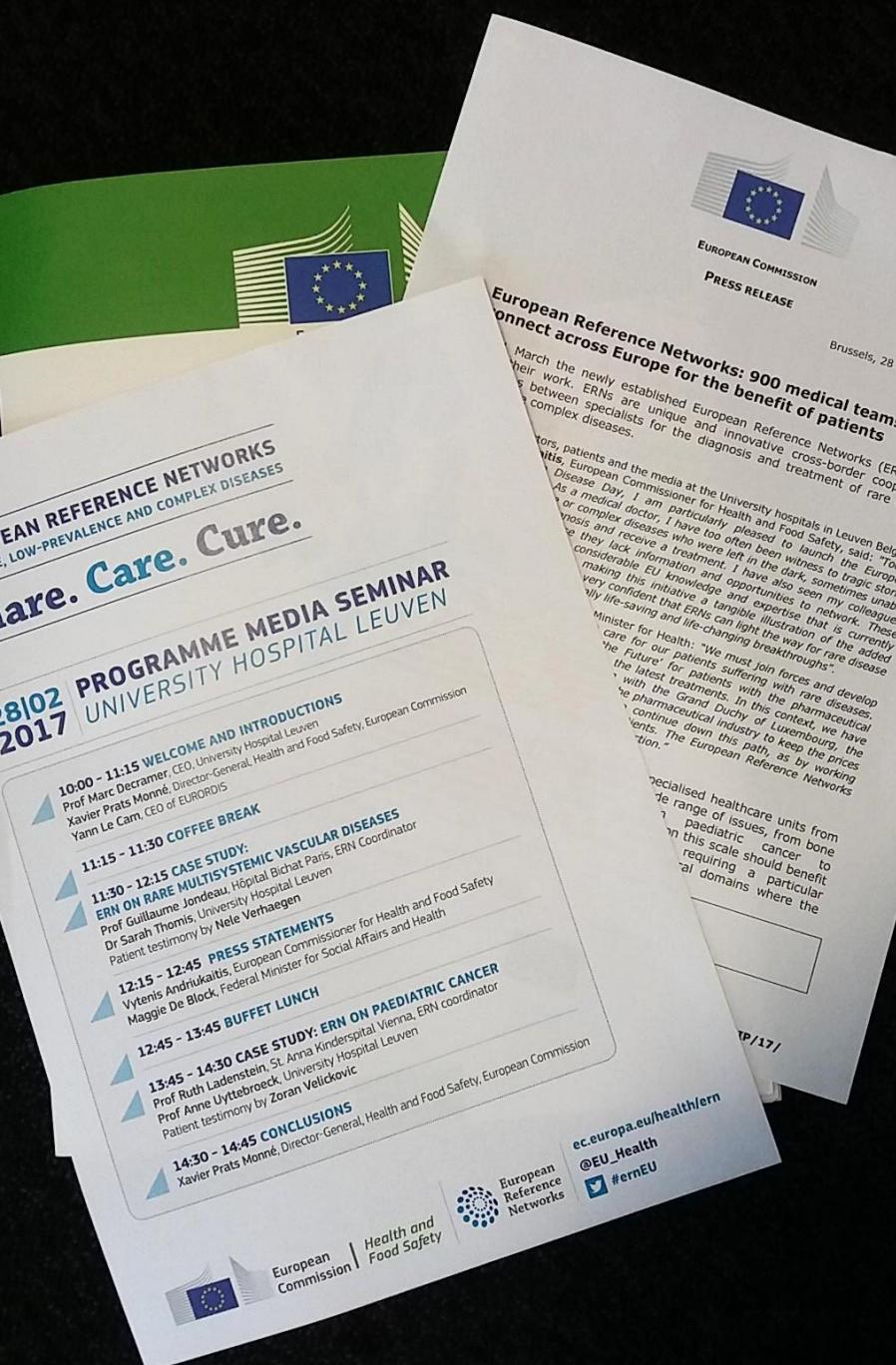
- **European Commission – DG SANTE**
- **European Commission Representations**



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)**

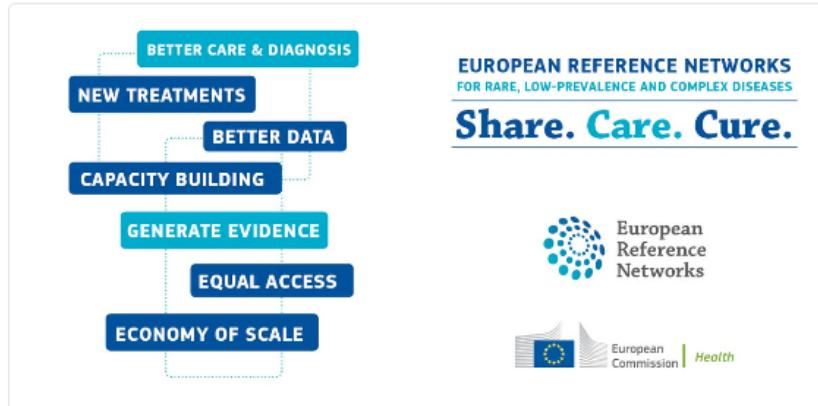


 **EU_Health** 
@EU_Health

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 bendriena. Po metų derybų pagaliau startuoja Europos referenciniai tinklai. Tikimasi, kad europinio masto bendradarbiavimo galimybės ir kaupiant žinias apie retų ligų gydymą aukštos kokybės paslaugas retomis ligoniams 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 diagnoosiminalates homsest lihtsamaks (7)

Silja Paavle, 28. veebruar 2017, 13:30

f JAGA LUGU!

t LISA TVITI

Prindi



-13:36

Trad.
tie

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

@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



Vytenis Andriukaitis @V_Andriukaitis

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

>300 HOSPITALS
>900 HEALTHCARE UNITS
THOUSANDS OF PATIENTS HELPED BY 2020

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

European Reference Networks

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

Working for patients with rare, low prevalence and complex diseases

ERN on kidney diseases (ERKNet)

Rare and complex kidney diseases comprise a wide range of congenital, hereditary and acquired disorders. It is estimated that at least 2 million Europeans are affected by rare kidney diseases, with glomerulopathies and congenital kidney malformations each accounting for approximately 1 million cases. In addition, inherited tubulointerstitial diseases, tubular-structural diseases and thrombotic microangiopathies represent a number of rare and ultra-rare diseases of high clinical relevance.

Online consultation services will improve management of new and complex cases.

In cases of suspected hereditary kidney disease, Working groups will then define clinical pathways for therapeutic management after thorough analysis of available treatments.

State-of-the-art diagnostic tools can provide valuable information about disease prognosis and therapeutic options. However, access to testing is not universal. Due to delayed diagnosis and delayed treatment, many rare kidney diseases progress to renal failure.

This ERN will seek to improve standards of diagnosis and treatment across Europe. The network will establish a consensus on national diagnostic algorithms for patients presenting with signs and symptoms of renal disease, including standard criteria for genetic testing.

Security Regulation: A series of webinars will be developed for teaching and training health professionals.

NETWORK COORDINATOR
Professor Franz Schaefer
Universitätsklinikum Heidelberg,
Germany

ЕВРОПЕЙСКИ РЕФЕРЕНТНИ МРЕЖИ
ЗА РЕДКИ, СЛАБОРАЗПРОСТРАНЕНИ И СЛОЖНИ ЗАБОЛЯВАНИЯ

Share. Care. Cure.

**REDES EUROPEIAS DE REFERÊNCIA
PARA DOENÇAS RARAS, COMPLEXAS E DE BAIXA PREVALENCIA**

Share. Care. Cure.

HOSPITAIS
300

UNIDADES DE CUIDADOS DE SAÚDE
900

MILHARES DE DOENTES TERÃO RECEBIDO AJUDA ATÉ 2020

European Reference Networks

Comissão Europeia | Saúde

European Commission - Fact Sheet

Questions and Answers about European Reference Networks

Brussels, 28 February 2017

On 1 March 2017 the first 24 European Reference Networks (ERNs) officially start their activities. Within these ERNs, more than 900 medical teams will join forces to treat patients with rare or low prevalence complex diseases or conditions.

What are European Reference Networks?

European Reference Networks (ERNs) are virtual networks involving healthcare providers across Europe. They aim to tackle complex or rare diseases and conditions that require highly specialised treatment and a concentration of knowledge and resources. Currently, 24 thematic ERNs are active, involving over 900 medical teams in more than 300 hospitals from 25 EU countries, plus Norway.

The Commission has created the framework for the ERNs and provides grants and technical networking facilities to support network coordinators. However, the driving forces behind the ERNs are healthcare providers and national health authorities. They show trust, take ownership and have the most active role in the development and functioning of the networks.

How can the ERNs improve the lives of patients?

Between 6 000 and 8 000 rare diseases affect an estimated 30 million people in the EU. An unfortunate feature of rare diseases and complex conditions is the scarcity and fragmentation of specialist knowledge, which is often not available in the patient's region or country. Many patients therefore do not find a satisfactory explanation for their symptoms or the necessary knowledge on treatment options. By consolidating knowledge and expertise scattered across countries, the ERNs will give healthcare providers access to a much larger pool of expertise. This will result in better chances for patients to receive an accurate diagnosis and advice on the best treatment for their specific condition.



European Reference Networks for rare and complex diseases



<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