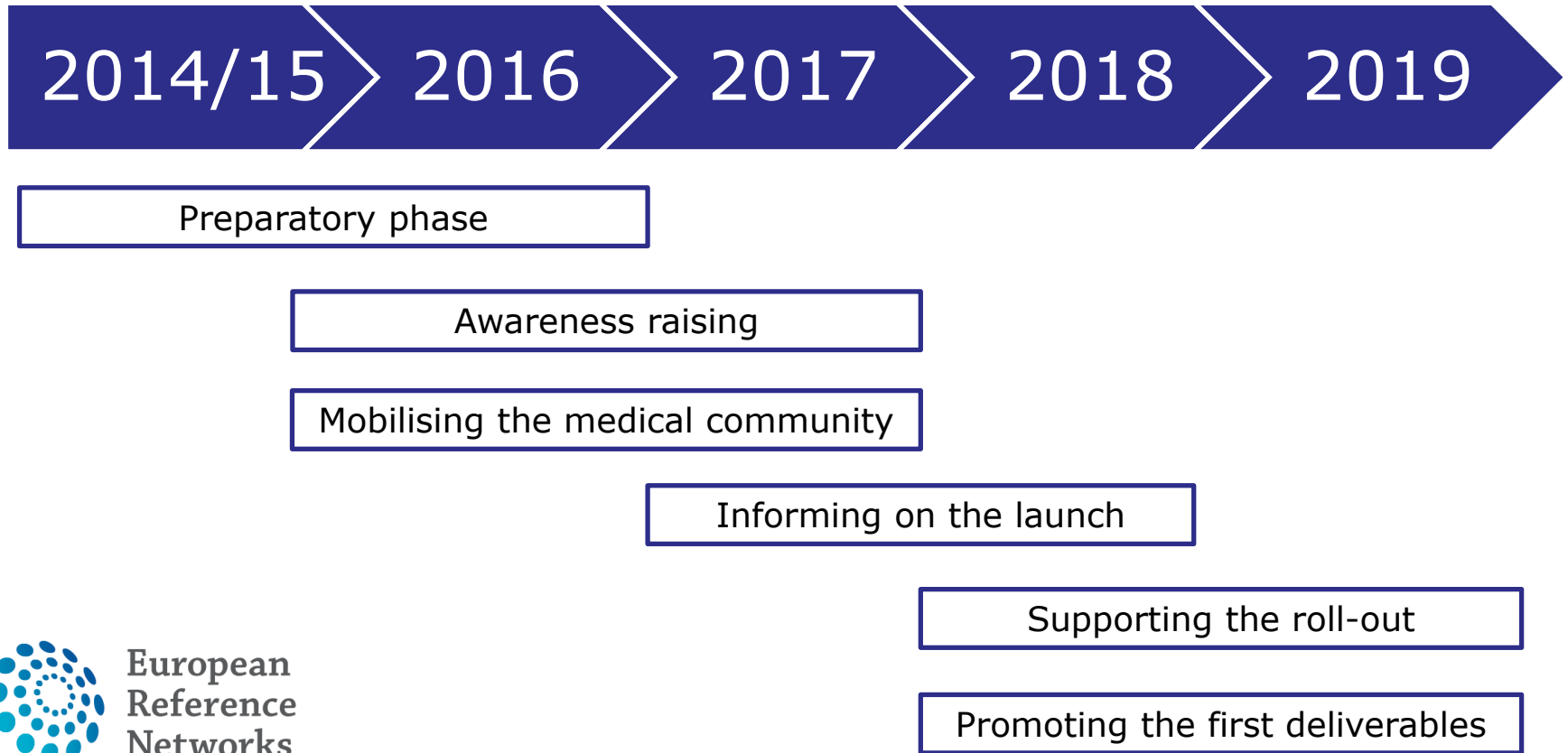


ERN Communication



Roser DOMENECH AMADO
Head of the Communication Unit
DG Health and Food Safety

ERN Communication



Information toolkit (2017-2018)

The image shows a blue infographic on the left and a white brochure on the right. The infographic lists statistics: > 300 HOSPITAIS, > 900 UNIDADES DE CUIDADOS DE SAÚDE, and MILHARES DE DOENTES TERÃO RECEBIDO AJUDA ATÉ 2020. The brochure features the title 'REDES EUROPEIAS DE REFERÊNCIA PARA DOENÇAS RARAS, COMPLEXAS E DE BAIXA PREVALÊNCIA' and the slogan 'Share. Care. Cure.' along with the European Reference Networks logo and the 'Comissão Europeia Saúde' logo.

> 300 HOSPITAIS

> 900 UNIDADES DE CUIDADOS DE SAÚDE

MILHARES DE DOENTES TERÃO RECEBIDO AJUDA ATÉ 2020

REDES EUROPEIAS DE REFERÊNCIA
PARA DOENÇAS RARAS, COMPLEXAS E DE BAIXA PREVALÊNCIA

Share. Care. Cure.

European Reference Networks

Comissão Europeia Saúde

A video player interface showing a video titled 'European Reference Networks for rare and complex diseases'. The video content features a group of diverse healthcare professionals standing against a blue background with yellow stars. The video player includes a progress bar at 00:20/01:33, a play button, a volume icon, and a full-screen icon.

European Reference Networks for rare and complex diseases

00:20/01:33

Information toolkit (2017-2018)

Communication toolkit for ERN Members, ERN BoMS, national focal points and Commission Representations

❖ Communication tips

- Communication tips for ERN Coordinators and Members 📄 🗨️

❖ Press communication

- Link to press release (in all EU official languages): "European Reference Networks: 900 medical teams to connect across Europe for the benefit of patients" (28 February 2017)
- Link to memo (28 February 2017)
- ZIP folder with 24 presentation fact sheets of the networks 🗨️ (available in all EU official languages and in Norwegian)
- Zip folder with posters presented at the 3rd Conference on ERNs (Vilnius, 9 March 2017)
- ZIP folder with lists ERN members per network
- ZIP folder with list ERN members per country

❖ ERN visual

- Zip folder with downloadable ERN visual

❖ General flyer

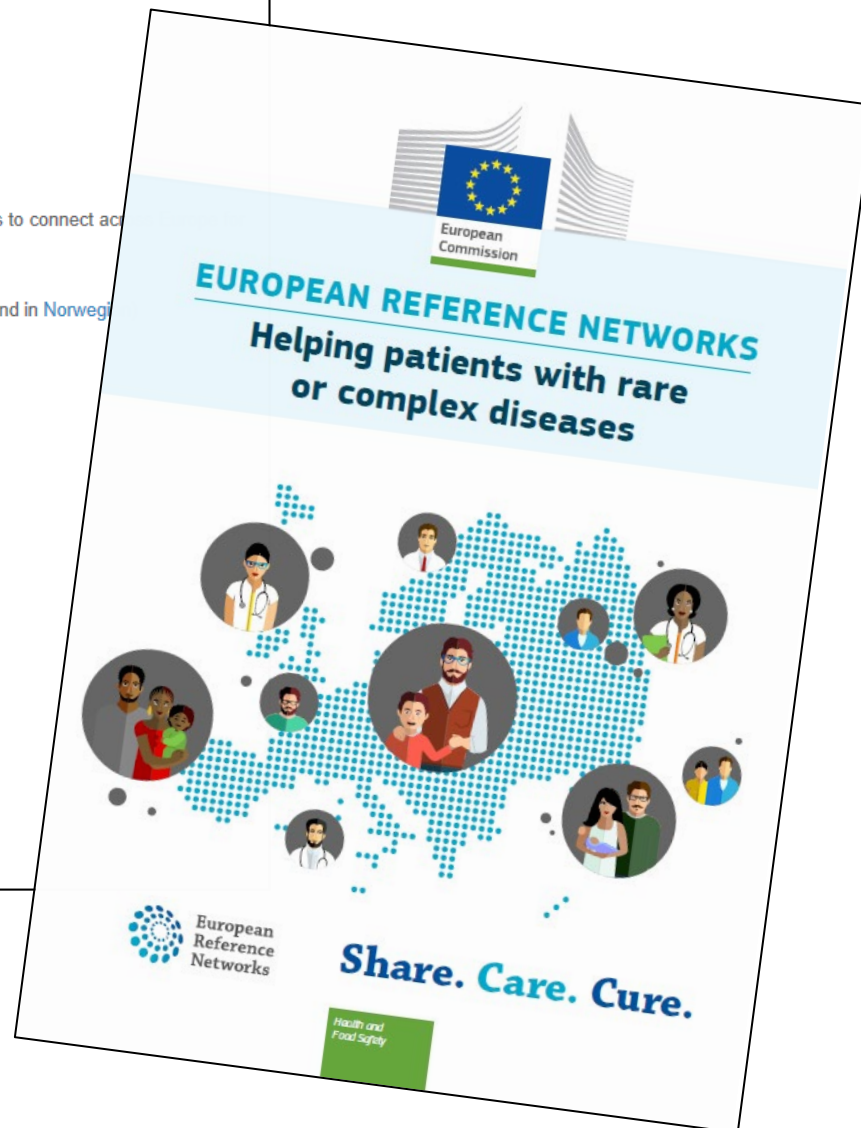
- ZIP folder with flyer in all languages – print version
- ZIP folder with flyer in all languages – web version

❖ Presentation brochure

- Web version in all EU languages 📄 🗨️ (Norwegian version 📄)

❖ Websites

- Basic guidelines for ERN websites 📄 🗨️
- ZIP folder with web banners (JPG)
- ZIP folder with web banners (EPS)



Media / social media communication

Localinfo MEDIA PARTICIPATIVE France Rechercher...

Offre spéciale nouveaux adhérents

MUTUELLE DU REMPART Licence sportive remboursée

LE FUTUR ASSURÉ

Article Accueil France

page précédente

05/07/2017 | France | Santé Vu 10076 fois

Réseaux européens de référence des malades et leurs familles

Les maladies rares... recherches et... définitif est un v...

Grâce aux Réseaux de personnes pa...

Il s'agit d'un ens... les patients, dar...




European Reference Networks

Leidsch Dagblad

Kennis over zeldzame ziektes geb...

Facebook Twitter Email



Nancy Ubert 29 sep. 2017

Snellere diagnose, betere behandeling en onderzoeksgegevens die makkelijk gedeeld kunnen worden. Specialisten uit de Europese landen gaan gericht en intensief samenwerken en kennis delen om mensen die aan een zeldzame ziekte lijden beter te helpen.

Heb je een zeldzame ziekte (binnen Europa wordt een aandoening als zeldzaam aangemerkt als minder dan 1 op de 2.000 mensen patiënt is) dan moet je soms jaren op de diagnose wachten. Vervolgens mag je hopen dat jouw arts precies weet wat hij moet doen.



ERN MEDIA SEMINAR
UNIVERSITY HOSPITALS LEUVEN



34 DRE VIDEO | ERN, la rivoluzione europea contro le...

MONDO

ERN, la rivoluzione europea contro le malattie rare

1 AGO 2017

Roma, (askanews) - Un sistema di piattaforme virtuali... alla quale i medici in... fidere informazioni sulle... la ricerca e le cure. È l'ERN... (orks), un'iniziativa della... mira a mettere in rete le... l'obiettivo di diminuire i tempi... no fino a 10 anni.

in sono così rare, soprattutto se... e del continente europeo. In... rsone per un totale di 8000... d'istituti solo pochi fondi... agnostica rapida e definitiva è... , ma anche per gli appena 150... are operanti in Italia. Nell'intera... ffetti da malattie rare tocca i 30... a troppo pochi i pazienti che... lizzate per le loro patologie.

e della Ssd di Genetica Medica... zoli di Bologna e... ond in Italia, la rete relativa alle... ento non abbiamo terapie


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Home / News / Health / Healthcare and austerity / Commission launches reference networks to face rare and complex diseases

Commission launches reference networks to face rare and complex diseases

By Hannah Black | EURACTIV.com 01-03-2017 Advertisement



EURACTIV Members

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- COCIR - European Coordination Committee of th...
- Cosmetics Europe - The Personal Care Association
- ECPC - European Cancer Patient Coalition
- EFA - European Federation of Allergy and Airway...
- EHFG - European Health Forum Gastein
- ESA - European Sunlight Association
- Medicines for Europe - Better Access. Better Hea...
- MedTech Europe - from diagnosis to cure

Popular articles

EU_Health @EU_Health Volg je nu

"By working together on rare diseases we can use the EU's great pool of knowledge and expertise".
 @V_Andriukaitis underlines added value of European Reference Networks #erneu

Tweet vertalen



06:08 - 10 sep. 2018

5 retweets 12 vind-ik-leuks

EU_Health @EU_Health Volg je nu

The first #EUfunded 24 European Reference Networks working for #raredisease patients all over Europe are now operational. What next?

Join the discussion @ the 4th #ERNEU conference, 21-22 Nov. in #Brussels.

More europa.eu/!Fy87Hq
 #EU #health #ERNs #ehealth

Tweet vertalen



04:30 - 16 nov. 2018

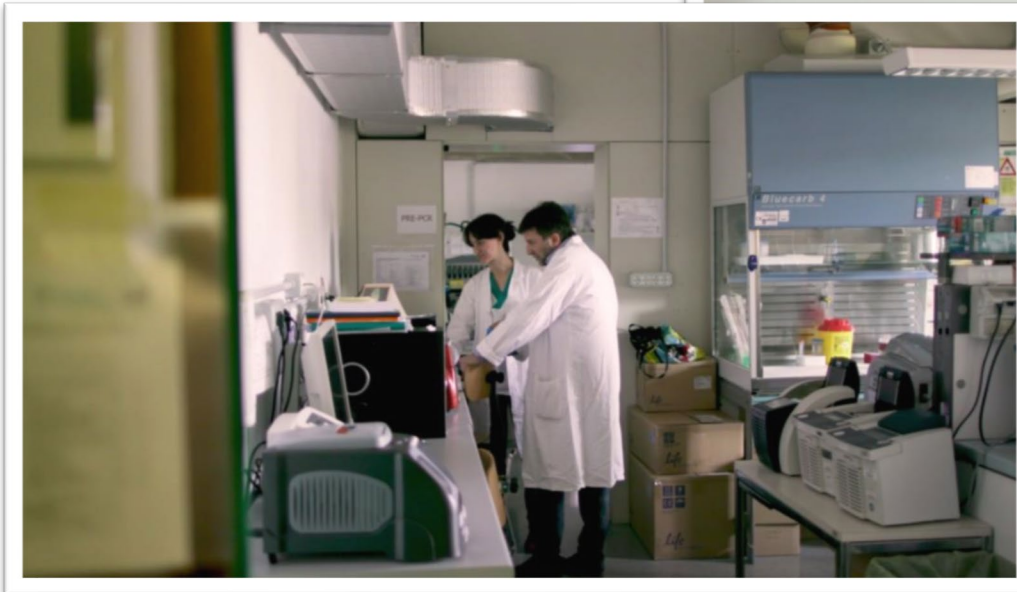
38 retweets 33 vind-ik-leuks

Vytenis Andriukaitis @V_Andriukaitis

We will work hard to ensure that... reach their potential, expand, and opportunities for more! bit.ly/2IGV



RETWEETS 15 LIKES 10



Impact

ERN launch:

→ 127K accounts reached

Promo animation video (Mar.-Apr. 2017):

→ 490K views

Promo reportages (Aug. 2017):

→ ES: 257K views

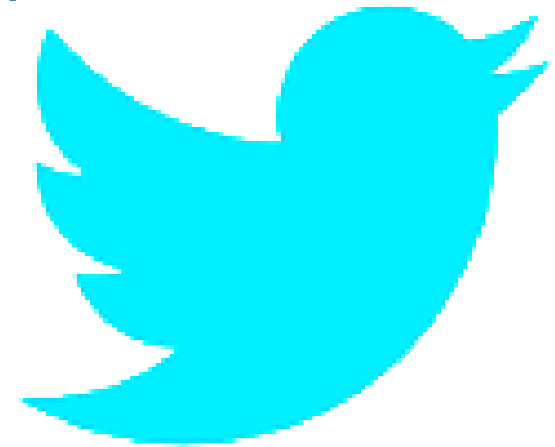
→ NL: 143K views

→ IT: 166K views

→ FR: 165K views

Rare Disease Day 2018 (Feb.-Mar. 2018)

→ 1 027K views



Impact

→ *Over 100K page visits
on the ERN web section
on www.europa.eu
(Jan. 2017 – Nov. 2018)*

European Reference Networks

[Home](#) [All topics](#) **Overview** [Work of the ERNs](#) [Networks](#) [Board of Member States](#) [Projects](#)

Overview

Health systems in the European Union aim to provide high-quality, cost-effective care. This is particularly difficult however, in cases of rare or low-prevalence complex diseases which affect the daily lives of around 30million EU citizens.

European Reference Networks (ERNs) are virtual networks involving healthcare providers across Europe. They aim to facilitate discussion on complex or rare diseases and conditions that require highly specialised treatment, and concentrated knowledge and resources.



❖ How does it work?

To review a patient's diagnosis and treatment, ERN coordinators convene 'virtual' advisory panels of medical specialists across different disciplines, using a dedicated IT platform and telemedicine tools.

The process and criteria for establishing an ERN and for selecting its members are set in EU legislation.









- Check our brochure   for more information

❖ 24 Networks

The first ERNs were launched in March 2017  , involving more than 900 highly-specialised healthcare units from over 300 hospitals in 26 EU countries. 24 ERNs are working on a range of thematic issues including bone disorders, childhood cancer and immunodeficiency.

- ERN members per network
- ERN members per country

❖ Legislation

- Directive 2011/24/EU on patients' rights in cross-border healthcare
- Commission delegated decision   (annex  ) defining the criteria and conditions that healthcare providers and the ERNs should fulfil
- Commission implementing decision   (annex  ) defining criteria for establishing and evaluating ERNs

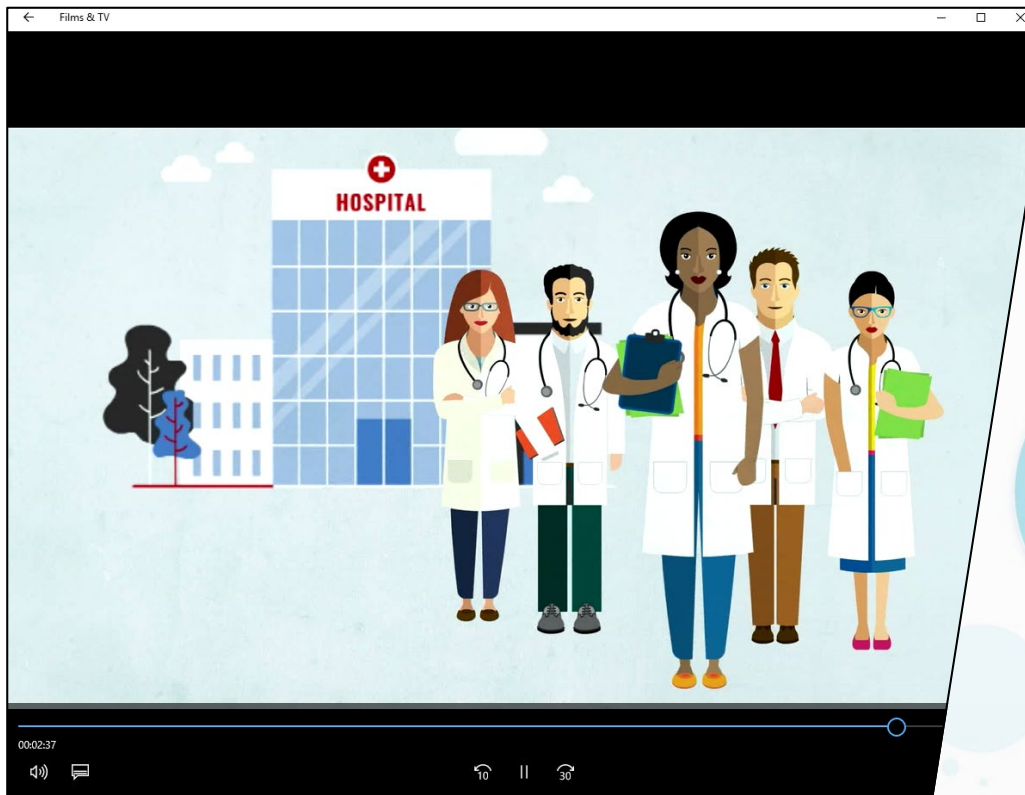
The ERN initiative receives support from several EU funding programmes, including the Health Programme, the Connecting Europe Facility and Horizon 2020.

❖ Coordination

The ERN initiative is mainly driven by EU countries. The Board of Member States is the formal body in charge of the approval and termination of networks and memberships as provided in the Commission's Implementing Decision. The Board is comprised of representatives of the 28 EU countries and the EEA countries.

❖ Related Information

What's next?





EU
TOGETHER WE
PROTECT



Lessons learnt and way ahead

- Importance of **concrete, visual and local** communication
- **Involvement of partners and multipliers:** ERN members, national health authorities, expert centres, patient and professional associations, hospital managers
- **Need for clear information** towards patients and healthcare sector



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



@EU_Health
#ernEU