



European
Commission



European
Reference
Networks



European Reference Networks for rare, low prevalence and complex diseases

Nora KAJTAR— European Commission

27 February 2018

Cross-border cooperation in Healthcare

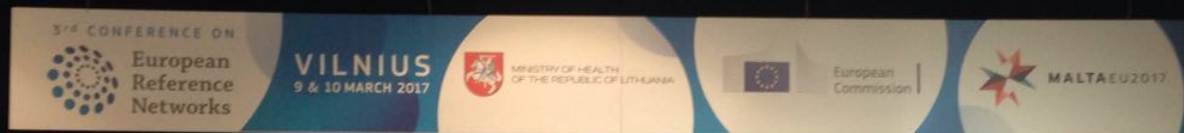
Directive ruled:

- Patients are entitled to choose a healthcare provider abroad.
- Patients should be reimbursed.
- Level of reimbursement should be at least equal to the cost of treatment at home.
- MS can require a patient to seek a prior authorisation.

Cooperation between MS

- Legal framework for cooperation:
 - Health Technology Assessment (HTA)
 - eHealth
 - **European Reference Networks (ERN)**

AWARD CEREMONY
3rd European Reference Networks Conference
9 March 2017 - Vilnius, Lithuania



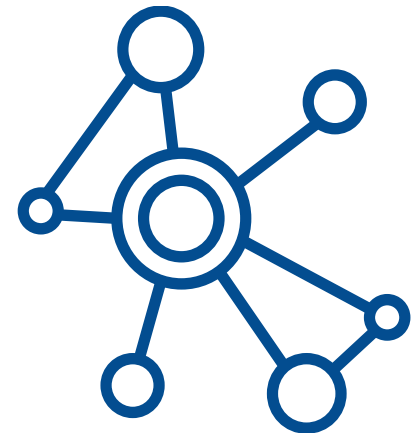


European
Commission

◆ WHAT?

Networking is the basis: "The knowledge travels, not the patient"

- ERNs are not directly accessible by patients, they are instead referred by healthcare providers.
- Networking, research and training.
- Virtual patient management software – **Clinical Patient Management System** – for the Networks to enable clinical patient work.





European
Commission

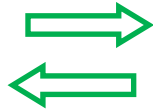


European Commission

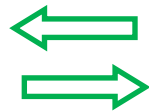
Actors involved in the ERN implementation



ERNs' Coordinators



ERNs Board of MS



European Reference Networks



European Commission

Health



The importance of patients in the ERN process

Working for patients with rare, low-prevalence and complex diseases

Focusing on improving patients' health outcomes: the role of patient organisations

ERNs are about patients. Patient organisations and, in particular, EURORDIS, have played an active role in the development of the networks for more than a decade, helping to ensure that the priorities will be to enhance clinical excellence and to improve patients' health outcomes and equitable access to quality care across Europe. EURORDIS is a non-governmental patient-driven alliance representing 733 rare disease patient organisations in 64 countries.

'We were there at the birth of the idea in the High-Level Working Group on Health Services and Medical Care, where ERNs were translated into the Cross-Border Healthcare Directive,' Mr Matt Bolz-Johnson, Healthcare and Research Director at EURORDIS recalls. 'We have walked the long road with Member States and the

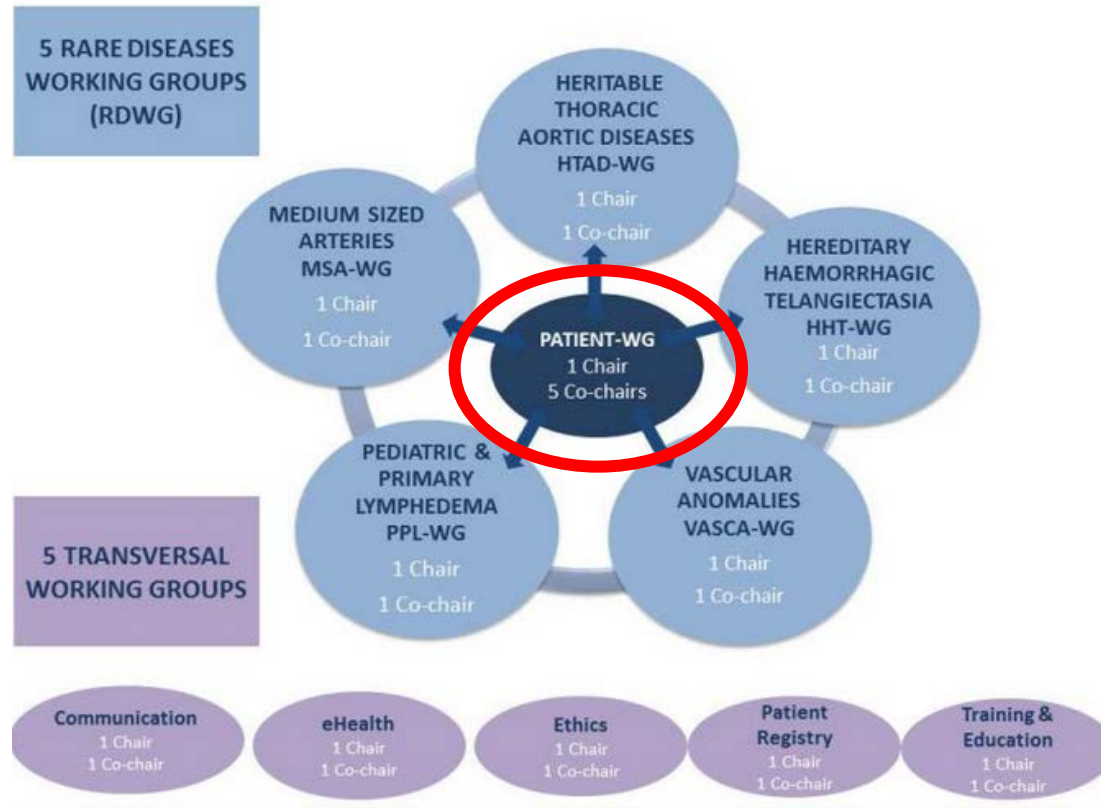
European Commission, from the birth of the concept into legislation, through to the germination of ERNs into reality.'

As a consistent partner in nurturing the concept of ERNs, EURORDIS has ensured patient involvement throughout and developed a strong technical understanding of how patients' engagement in the networks can add real life value for patients.

'Networks have the potential to unlock tangible benefits for patients with rare and complex presentations of disease,' says Mr Bolz-Johnson. 'ERNs will break the isolation that rare disease communities face and make experts visible to patients across Europe, magnetising patient needs to the right experts quicker.'

'Networks have the potential to unlock tangible benefits for patients with rare and complex presentations of disease.'

Patients in the ERN governance: the example of VASCERN





**European
Reference
Networks**

http://ec.europa.eu/health/ern/policy/index_en.htm

nora.kajtar@ec.europa.eu

SANTE-ERN@ec.europa.eu



European
Commission