

Press release following the rare diseases day and 1 year anniversary of ERNs

European press:

Parliament magazine, 20 February 2018:

<https://www.theparliamentmagazine.eu/articles/opinion/rare-disease-research-european-reference-networks-are-good-start>

European Commission, 28 February 2018:

http://ec.europa.eu/newsroom/sante/newsletter-specific-archive-issue.cfm?newsletter_service_id=327&newsletter_issue_id=7438&page=1&fullDate=Wed%2028%20Feb%202018&lang=default

Politico Pro, 1 March 2018:

RARE DISEASE NETWORKS, ONE YEAR IN: The computer networks are up and running and rare disease patients are starting to enter their data. A year after their launch, the European Reference Networks are looking ahead to what it will take to truly perform their mission: connect patients with the Continent's top experts, no matter where they live. Health Commissioner Vytenis Andriukaitis is one of the ERN's biggest cheerleaders; he envisions them as the "backbone" of a broader pan-European health data network. Yet Andriukaitis was clear-eyed Wednesday about the three immediate challenges facing the ERN as they enter their next phase.

The first, he said, is making sure the ERN are integrated into national and regional health systems. Member countries need to assess whether they need to change their laws to aid success. It's not yet clear how patients get referred into the ERN, and the exact definition of how member countries support the ERN is still murky.

Hospital support is the No. 2 challenge for the ERN, Andriukaitis said, with hospital managers as "key players."

Finally, and perhaps most politically important, is pulling other countries into the networks. Right now, 25 EU countries and Norway are part of the 24 networks. A big concern has long been that the "centers of excellence" — the hubs of the ERN spokes — will be disproportionately in Western and Northern European countries. Andriukaitis said the Commission is planning to launch a call for new ERN members to join at the end of 2018. "We need to ensure that new members bring new knowledge into the networks and increase the geographical coverage," he said at Wednesday's event, hosted by the patient group EURORDIS. In patients' own countries, he added, "networks need to become stronger, more productive and more accessible."

National coverage:

Italy (Panorama Sanità), 1 March 2018:

<http://www.panoramasanita.it/2018/03/01/malattie-rare-oggi-il-primo-anniversario-delle-reti-di-riferimento-europee-gia-operative-24-ern/>

Croatia (Vecernji), 1 March 2018:

<https://www.vecernji.hr/vijesti/europski-dan-rijetkih-bolesti-ern-vytenis-andriukaitis-1229685>

Portugal (Público), 2 March 2018:

<https://www.publico.pt/2018/03/01/sociedade/opiniao/um-ano-de-redes-europeias-de-referencia-para-as-doencas-raras-1804781>

Bulgaria (Forum Medicus), 7 March 2018

<http://forummedicus.com/>

Commission representations in Member States:

France: https://ec.europa.eu/france/news/20180228_maladies_rares_fr

United Kingdom: https://ec.europa.eu/unitedkingdom/news/first-anniversary-eu-health-network-harnesses-knowledge-and-expertise-help-thousands-patients_en

Italy: https://ec.europa.eu/italy/news/20180228_giornata_europea_malattie_rare_it

Spain: https://ec.europa.eu/spain/news/180228_eu-day-rare-diseases-2018_es

Czech Republic: https://ec.europa.eu/czech-republic/news/180228_ERS_pro_vzacna_onemocneni_cs

Ireland: https://ec.europa.eu/ireland/news/european-rare-disease-day-2018_en

Luxembourg: https://ec.europa.eu/luxembourg/news/journ%C3%A9e-europ%C3%A9enne-des-maladies-rares-2018-premier-anniversaire-des-r%C3%A9seaux-europ%C3%A9ens-de_fr