

SPEECH | 28 February 2018

SPEECH AT RARE DISEASE EVENT IN THE EUROPEAN PARLIAMENT - BRUSSELS - WEDNESDAY 28 FEBRUARY 2018

Check against delivery.

Honourable Member (Dear Ms Gentile),

ERN Coordinators,

Ladies and Gentlemen,

I am honoured to be here on European Rare Disease Day 2018. I thank MEP Gentile for hosting this event.

I am a great believer in – and supporter of – the European Reference Networks for rare, low prevalence and complex diseases.

I warmly welcome the opportunity to learn more on the findings of the White Paper on Diagnosis that the ERN BOND is presenting today.

Let me thank Dr Sangiorgi for the incredible work that the ERN BOND is doing in enhancing care for patient suffering from rare bone diseases. I am glad to know that patients are welcoming this ERN with such enthusiasm. I still remember Rebecca's speech last year in Vilnius and our recent meeting in Oslo.

Indeed, patients are the heart of this project and they always have been equal partners. They helped us create and steer the concept of the

European Reference Network and today they work together with healthcare professionals, hospital managers and Member States in the day-to-day functioning of the Networks.

Since the beginning of this journey, EURORDIS has been helping us to define the priorities of this project and shape its construction. I would like to say a BIG thank you.

Exactly one year ago I was at Leuven University Hospital with the Belgian Minister of Health – Madam De Block – to launch the European Reference Networks.

Today I am with you to celebrate one year of success of the 24 ERNs that are now operating across Europe.

I am extremely grateful for the continuous work that you are doing for patients, alongside healthcare professionals, researchers, policy makers and hospital managers – working together to improve the quality of life of millions of people in Europe suffering from a rare disease.

Since the adoption of the Cross-Border Healthcare Directive in 2011 we have come a long way:

- We built a legal framework for the ERNs;
- We launched the first call and the ERN Board of Member States approved the 24 Networks;
- Today these Networks are operational and we see first patients are now directly benefiting from this European innovative cooperation.

Of course, we still have a long way to go – but we have certainly made a most promising start!

Let us look, for example, at what has been achieved in the area of clinical care:

The Networks' key IT tool – the Clinical Patient Management System – was launched on 20 November 2017, and by now already 67 consultation panels have been opened.

On knowledge generation and knowledge sharing, by gathering a pool of patient data, ERNs are already very well placed to facilitate large clinical studies to improve the understanding of diseases and support the development of new medicinal products.

Now that the framework is in place and the ERNs are up and running, we need to focus on how to maximise their effectiveness and ensure their sustainability.

Today I want to highlight **three immediate challenges**.

The **first** and most important challenge is to ensure the integration of ERNs into national or regional healthcare systems. This includes:

- Assessing changes required in the legal framework of each Member State to properly integrate ERNs into their healthcare systems;
- Deciding on the pathway and mechanism for referring patients to an ERN; and
- Defining how Member States support the ERNs.

I can assure you that the Commission is very active at technical, strategic and political level to help national authorities speed up the process of integration.

The **second** challenge is to ensure full support to the ERNs.

Hospital managers are key players in the success of the ERNs, many of whom already fully appreciate the benefits that ERNs will bring to their hospitals and to their healthcare systems. I want to thank them for the tangible support they are offering ERN members.

However, to fully unlock the potential of ERNs we have to make sure that hospital managers, with our support, coordinate their efforts.

We started a fruitful collaboration with hospital managers last November

in Rotterdam and will continue working together to ensure that ERNs get full support from their local managers.

The **third** challenge I want to raise concerns the selection and integration of new members in the 24 current ERNs.

Highly specialised centres not included in the first approved Networks have the opportunity to apply to participate in the work of approved ERNs. In this regard the Commission is planning to launch a new call towards the end of this year.

We need to ensure that new members bring new knowledge to the ERNs and increase their geographical coverage so that more patients have access to the ERNs in their own country. ERNs need to become stronger, more productive and more readily accessible.

And finally, let me also stress the need to further link ERNs to other important EU projects in the future, such as the European High Performance Computing or the European Research Infrastructures.

President, Ladies and Gentlemen,

I am fully aware that we still have a great deal to do. Collaboration across all the different European healthcare systems is not always easy and sometimes bureaucracy can be extremely burdensome.

But in the face of such difficulties we need to stay focussed, always mindful of the main goal – to increase the likelihood of early and accurate diagnosis and the effective treatment of patients suffering from rare diseases.

At the same time, ERNs are best placed to facilitate large clinical studies to improve understanding of diseases and support development of new care models and innovative medical solutions.

In the future, we can use ERNs as backbone for building a European Health Data Eco-system and initiating better networking between and within Member States' healthcare systems.

Thank you for your attention.

I wish you all a fruitful meeting and hope to see you at the 4th ERN Conference to be held here in Brussels in November.