

## EuropaBio Patient BioForum: challenges and future potential of European Reference Networks

### NEWS RELEASE

**Brussels, 19 October 2021**

On the **19<sup>th</sup> of October 2021**, in view of the evaluation of European Reference Networks (ERNs) expected in 2022/23, EuropaBio invited patient organisations, industry, EU institutional and Members State representatives to engage in a discussion on the challenges and future potential of the Networks.

Nicola Bedlington, former Secretary General of the European Patients' Forum, and founding partner of Millwater Partners moderated the event comprising an expert panel:

- Ingunn Westerheim, President of the umbrella organisation Osteogenesis Imperfecta Federation Europe;
- Dr Birute Tumienė, clinical geneticist at the Centre for Medical Genetics and the Coordinator for Competence Centres in Vilnius University Hospital Santaros Klinikos, ERN Board Member on behalf of Lithuania, Eurordis Black Pearl Awardee 2021;
- Dirk Vander Mijnsbrugge, Vice President Medical Affairs Lead Rare Diseases International Developed Markets, Pfizer;
- Dr Jose A. Valverde, Policy Officer, European Reference Networks and Digital Health, DG SANTE, European Commission;
- Assoc. Prof. Dr Till Voigtländer, Neurobiologist and Neuropathologist at the Department of Neurology, Medical University of Vienna; ERN Board Member on behalf of Austria, current co-chair of the Board of Member States, Eurordis Black Pearl Awardee 2019.

ERNs were created with a vision to enable patients across Europe to access virtual networks consisting of highly specialised healthcare professionals to assist in the diagnosis and treatment of rare and complex diseases. Having first launched in 2017, ERNs have already demonstrated the power of collaboration in the diagnosis of complex and rare diseases. Notwithstanding their initial success, ERNs face operational issues in terms of long-term functionality, including challenges related to funding, data sharing, and governance which are key to ensure their future growth.



Described as a “disruptive innovation” for patients by Drs Birute Tumienė and Till Voigtländer, panellists highlighted practical examples of how rare disease patients can seek healthcare advice via ERNs and the challenges they face. While the initial success of ERNs was unwarranted, with applications from 24 Networks in 2017, there are challenges of implementation that require time and effort from all stakeholders to understand and tackle. The importance of open dialogue to address ongoing problems is crucial in areas such as the exchange of patient data and privacy, and the importance of sustainable and predictable funding.

While the Member States have already invested resources in ERNs, continuing their integration within national healthcare systems, and allocation of resources as part of the EU4Health programme will be important to ensure sustained success. Ms Westerheim spoke to the issues which face national integration and functioning of the Networks with regard to data sharing but also post-Brexit with the loss of numerous experts.

Collaboration with industry is key to the successful continued development of the ERNs which can contribute to research and development in the rare disease space. Mr Vander Mijnsbrugge pointed out the need to properly reflect on the inclusion of ERNs within healthcare policy review at the EU-level if Europe wants to be at the front in this field, it can be only successful if it engages in a partnership with the industry.

Dr Valverde, and indeed all panellists, stated the importance of taking the time for evaluation and assessment of what has been done until now to build ERNs and what can be done to improve their functionality for the patients in the future.

The event report will be published in the coming weeks, with a recording of the event immediately available <here>.

**ENDS**

---

### Media contact

Dovile Sandaraite, Communications Manager | Email: [d.sandaraite@europabio.org](mailto:d.sandaraite@europabio.org)

### About EuropaBio

EuropaBio, the European Association for Bioindustries, promotes an innovative and dynamic European biotechnology industry. EuropaBio and its members are committed to the socially responsible use of biotechnology to improve quality of life; to prevent, diagnose, treat, and cure diseases; to improve the quality and quantity of food and feedstuffs and to move towards a biobased and zero-waste economy. EuropaBio represents corporate and associate members, plus national biotechnology associations and bioregions.

Read more about our work at [www.europabio.org](http://www.europabio.org).

