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The recognition of Belgian Reference Centers of Clinical Pathology improves the quality of the biochemical diagnosis of rare diseases

Nathalie M. Vandevelde

Scientific Institute for Public Health (Sciensano), Belgium

Introduction: In Europe, rare diseases (RD) are defined as disorders affecting less than 1 patient in 2000 individuals. More than 50% of them affect children. Their diagnosis is often delayed because of their complexity. In 2017, Sciensano, the Belgian Institute for Public Health, was mandated by the Belgian healthcare authorities to select new National Reference Centers (NRC) for some highly-specific biochemical analyses of clinical pathology used for RD. In 2019, 18 NRC for RD have been recognized by the Belgian Healthcare authorities for a 5-year renewable term.

Method: In the context of its missions of follow-up, support and guidance, Sciensano annually collects data and information from the 18 NRC for RD (annual volumes of analyses, costs, quality management, possible needs). Then, Sciensano establishes new partnerships between these NRC and foreign European academic medical laboratories in order to improve some specific aspects of the missions of the NRC.

Results: Between 2019 and 2022, the official recognition and follow-up of these NRC led to 3 key achievements in the quality of the diagnosis of some specific RD: (i) the development of stable annual international quality controls for analyses performed by 7 NRC, when these controls were previously unavailable; (ii) 82.8% increase in the accreditation of the NRC according to the norm ISO15189; (iii) international partnerships with 9 foreign academic medical laboratories for the outsourcing of medical analyses used for RD and unavailable in Belgium.

Conclusion: The NRC recognition improves the management of RD and the share of knowledge between international clinical experts.

Biography

Dr. Vandevelde received her Master and PhD degrees in pharmaceutical sciences from the Université catholique de Louvain (Belgium) and a university degree in clinical research from Harvard University (Boston, MA). Since 2015, she works at the Belgian Scientific Institute of Public Health, called Sciensano. She has developed health economics models in order to improve the access of patients with rare diseases to diagnostic tests. She is responsible for different international scientific and clinical projects and in charge of the selection, financing, and follow-up procedures for the Belgian National Reference Centers for Rare diseases.

nathalie.vandevelde@sciensano.be

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