

European References Networks – Rare Diseases

Between 5 000 and 8 000 rare diseases affect the daily lives of around 30 million people in the EU. For example, in the field of oncology alone, there are almost 300 different types of rare cancers and each year more than half a million people in Europe are diagnosed with one of them. Many of those affected by a rare or complex condition do not have access to diagnosis and high-quality treatment. Expertise and specialist knowledge may be scarce because patient numbers are low.

The EU and national governments are committed to improving the recognition and treatment of these rare and complex conditions by strengthening European-level cooperation and coordination and supporting national plans for rare diseases.

The 2011 Directive on Patients' Rights in Cross-border Healthcare not only enables patients to be reimbursed for treatment in another EU Member State but also makes it easier for patients to access information on healthcare and thus increase their treatment options. The Directive became law in EU Member States in 2013 and emphasises the value of eHealth and the importance of interoperability in national health IT systems in facilitating information sharing. It is against this backdrop that, with the support of the EU Health Programme, the first 24 European Reference Networks started their activities in 2017.

European Reference Networks (ERNs) are virtual networks involving healthcare providers across Europe. They aim to tackle complex or rare diseases and conditions that require highly specialised treatment and a concentration of knowledge and resources.

To review a patient's diagnosis and treatment, ERN coordinators convene 'virtual' advisory boards of medical specialists across different disciplines, using a dedicated IT platform and telemedicine tools.

No country alone has the knowledge and capacity to treat all rare and complex diseases. ERNs offer the potential to give patients and doctors across the EU access to the best expertise and timely exchange of life-saving knowledge, without having to travel to another country.

Following the first call for proposals in July 2016, the first ERNs were approved in December 2016 and launched in March 2017 in Vilnius where their kick off meetings took place. At their inception, the networks comprised more than 900 highly specialised healthcare units located in 313 hospitals in 25 Member States (plus Norway). 24 ERNs are working on a range of thematic issues, including bone disorders, childhood cancer and immunodeficiency. Over the next 5 years, ERNs are expected to reinforce their capacities to benefit thousands of EU patients suffering from a rare or complex condition. Calls for healthcare providers wanting to join existing ERNs will be launched yearly.

After a quite stringent selection process the University Hospital of Padua has been included among the members (Health Care Provider) of 22 of the 24 ERN presently activated. This excellent result is the end product of a national and regional policy tackling the main issue related to patients affected by Rare Disease, of the Coordinating Center for Rare Diseases of the Veneto Region and ultimately but not lastly the quality the high standard of care provided by the University Hospital of Padua, thanks to the quality of its medical personnel, to the sophisticated technique equipment, to the level and quality of internal organization and to the strong cooperation with the University of Padua.

This large participation of the University Hospital of Padua to so many ERN has project the hospital

itself into a European panorama which is becoming richer and richer of opportunities for improving the health status of our population.

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