

## **Article for REPs**

### **Rare Diseases Day 2019:**

#### **Two years anniversary of the European Reference Networks for rare and complex diseases**

**By Vytenis Andriukaitis, European Commissioner for Health and Food Safety**

This is not an article about a disease. This is a story about Onni<sup>1</sup>, a five-year-old boy from Finland with a rare form of epilepsy.

Onni's parents first took him to a private doctor who did not have the necessary expertise to treat his illness, and therefore referred him to a paediatrician. The paediatrician found himself in the same situation and referred the small boy to one of the five university hospitals in Finland - the neurology department of Helsinki Children's Hospital. The neurologist in charge consulted Kuopio University Hospital. Onni's story could have ended there, at Kuopio Hospital. Like millions of patients with a rare disease, his parents could have spent ten years searching for the correct diagnosis or treatment for him. Fortunately, it took only two and a half years to get him the right help. In fact, Onni benefited from the very first experiment of this kind in Europe, as the doctors in Kuopio hospital decided to consult EpiCARE, the European Reference Network for epilepsy.

Launched in 2017, the European Reference Networks (ERNs) are virtual networks involving healthcare providers across Europe. 24 networks covering 24 different disease groups from bone disorders to haematological diseases, from paediatric cancer to immunodeficiency, have been established so far. They include 956 highly specialised healthcare units in 313 hospitals across 26 countries (25 EU Member States plus Norway). They offer patients and doctors across the EU access to the best expertise and timely exchange of life-saving knowledge through virtual consultations and knowledge sharing, with neither the patient nor the doctor having to travel abroad.

But let me be frank here - although the ERNs are a success story at EU level, in order to be fully operational and effective they need to be adequately integrated into national health systems. This means that Member States would need to include ERNs in their national plans on rare diseases and provide support to ERN members and coordinators. In addition, because ERNs are not directly accessible to individual patients, Member States would need to make sure that in case of need, a patient could be taken from his primary medical contact point to a hospital that can refer the patient to the relevant ERN. And last but not least, Member States need to reach out to all levels of healthcare providers to raise awareness on ERNs and to make the patient pathways and referral widely known, as the case in Finland showed us.

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<sup>1</sup> The name of the child has been changed but his story is real and can be seen in the video promoted through the EU protects campaign: <https://ec.europa.eu/avservices/video/player.cfm?sitelang=en&ref=I164244>

What does Onni's case tell us? Even though Onni's parents had to go a long way before getting the right diagnosis and treatment, the way the Finnish health system is organised and its connection with the EpiCARE network was very helpful in streamlining the delivery of care.

Another important element in this case is the good level of awareness of the existence of the ERNs, and its clear complementarity to the national health system. Both the doctor caring for Onni at Helsinki Children's Hospital and the doctor who introduced his case to EpiCARE network at Kuopio University Hospital confirm that the possibility to consult European health professionals remotely through ERNs is quite widely known among specialists in the Finnish health system, especially at university hospitals.

But while Finland is a good example of a well-functioning system, there is no unified or commonly agreed conceptual model for integrating ERNs into health systems in Europe. The landscape of integration and accessibility of ERNs varies widely across the EU. And some Member States will have to invest more than others to achieve a mature system.

I therefore call on Member States to reach out, learn from one another and invite each other to build solid referral pathways that could enable patients even in the poorest or most remote areas to be treated by the best specialists in Europe.

For Onni, the European Reference Network provided life-changing help, without which he would not have been able to get the specific medical treatment for his epilepsy. Let us now make this a reality for all the patients struggling with a rare or complex disease. Let us make good use of the European Reference Networks.

More information on the European Reference Networks:

[https://ec.europa.eu/health/ern\\_en](https://ec.europa.eu/health/ern_en)