



St. Anna Kinderkrebsforschung
CHILDREN'S CANCER RESEARCH INSTITUTE



Press Release

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European Health Initiative put to the test. St. Anna Children's Hospital as the Driving Force.

On Monday 10 September 2018, EU Commissioner for Health and Food Safety, Vytenis Andriukaitis met with medical experts and people directly affected by childhood cancer at St. Anna Children's Cancer Research Institute in Vienna, Austria.

A critical discussion about successes and hurdles to improve medical care for children with cancer.

The development and future of the European Network against Childhood Cancer (ERN PaedCan) was the focus of an expert discussion with EU Commissioner for Health and Food Safety, Vytenis Andriukaitis, people directly affected by childhood cancer, and medical experts.

How it all started: Vytenis Andriukaitis, medical doctor by profession, launched the European Reference Networks for Rare Diseases (ERNs) in March 2017. The 24 networks bring together more than 900 highly specialised units from 300 hospitals across Europe. This bundling of medical expertise is intended to benefit patients suffering from a rare or highly complex disease and requiring highly specialised health care.

"Working together on rare diseases is an area of enormous EU-added value: we can use the EU's great pool of knowledge and expertise by connecting our assets through ERNs. This has already brought concrete benefits to a number of patients and we strive to help more", said the Commissioner during his visit of St Anna Hospital.

Austria is currently involved in two ERNs. One of them, ERN PaedCan, is coordinated by the St. Anna Children's Hospital and the St. Anna Children's Cancer Research Institute. Its aim is to ensure equal access to high-quality health care for children with cancer throughout Europe, since – due to low patient numbers and a lack of resources and specialized expertise – the chances of cure are still unequally distributed. This can only be achieved by promoting cooperation, research and education. "And this is exactly where we reach our limits. International medical cooperation requires not only high-quality digital networking, but also a suitable virtual communication platform that enables the transmission of large amounts of data and live communication in virtual advisory bodies, so-called 'tumour boards". Univ.-Prof. Dr. Ruth Ladenstein, ERN PaedCan Coordinator explains: "ERN PaedCan identifies centres of expertise in Europe in the spectrum of haemato-oncological diseases and makes them visible and accessible via the relevant web pages of SIOPE and ERN PaedCAN ('Road Maps'). In addition, the technical platform for virtual tumour boards provided by the European Commission will be introduced to the European Community of Pediatric Haemato-Oncologists in order to ensure rapid and well-founded cross-border counselling, but also specific assistance regarding therapy adoption, in response to inquiries from European centres on complex patient cases with the help of the ERN PaedCan expert centres."

"Twinning programmes by European centres of expertise with hospitals from developing countries are also a decisive measure to ensure that all childhood cancer patients receive the same quality of



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European
Reference
Network

treatment" adds Prof. Dr. Wolfgang Holter, Medical Director of the St. Anna Children's Hospital and Head of the St. Anna Children's Cancer Research Institute.

"Another important aspect is, for example, the country-specific establishment of the so-called 'Survivorship Passport' in Austria which has been included in ELGA, the electronic health file. The 'Survivorship Passport' is a condensed doctor's letter, developed jointly with survivors of childhood cancer, that summarises diagnosis, treatment and possible long-term consequences and helps those affected to receive better medical care in the future on the basis of concise medical information. Early prevention measures following cancer therapies can reduce the burden of long-term consequences," says Carine Schneider, a former childhood cancer patient. The 'Survivorship Passport' was included in the 'Austrian National Cancer Plan' in 2014.

In Europe, Austria is at the forefront of medical care for childhood cancer. The admission of suitable new partners to the network guarantees excellence in medical research and care.

European Reference Networks (ERN)

These are virtual networks of healthcare providers throughout Europe. Their aim is to enable the management of complex or rare diseases or health problems which require highly specialised treatment and know-how. So-called ERN coordinators convene "virtual" advisory board meetings of medical specialists from various fields to provide multidisciplinary advice on diagnosis and treatment. New tools from the e-health and telemedicine fields facilitate coordination.

https://ec.europa.eu/health/ern/overview_en

St. Anna Children's Hospital

In 1837, in the former Viennese suburb of Schottenfeld, St. Anna was the first children's hospital in Austria and the third independent hospital in Europe to focus exclusively on children's health. Since then, the St. Anna Children's Hospital has developed into an institution offering state-of-the-art medical care. In addition to being a general children's hospital, the Centre for Pediatrics and Adolescent Medicine has been able, over the past 40 years, to establish an excellent national and international reputation as a centre for the treatment of childhood blood and tumour diseases (cancer). www.stanna.at

St. Anna Children's Cancer Research Institute

The St. Anna Kinderkrebsforschung develops and optimises diagnostic, prognostic and therapeutic strategies for children and adolescents suffering from cancer by combining basic research with translational and clinical research. The focus is on the specific characteristics of childhood tumor diseases in order to offer young patients the best and most cutting-edge treatment options available. More information can be found at <http://science.ccri.at>.