



Improving the care of children with rare cancer through collaboration



www.raretumors-children.eu



Co-funded by
the Health Programme
of the European Union

This brochure is part of the project 777336/PARTNER which has received funding from the European Union's Health Programme (2014-2020).



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WHAT IS PARTNER?

PARTNER is a 3-year project that will create a **Paediatric Rare Tumour European Registry** dedicated to children and adolescents with VRT (Very Rare Tumours).

Expected outcomes:

- **Creating a comprehensive EU platform** dedicated to the improvement of care for children and adolescents with VRT
- **Harmonising data in the existing national registries** in collaboration with the JRC registry platform
- **Linking the EU registry** with a virtual consultation system
- **Providing a registry** for those countries that do not already have a registry for VRT in place
- **Enabling detailed** diagnostic/treatment recommendation that can be easily accessed by EU healthcare providers
- **Increasing the capacity** to provide international consultation and fostering access to expert diagnosis, and treatment improving the chances of cure for children with VRT across Europe
- **Improving care for patients and reducing inequalities** in cancer outcome across EU Member States

STAKEHOLDERS

- **6** Associated partners
- **18** Collaborating partners
- **9** LHEAR countries
- **2** Non-EU countries
- **1** Parent organisation

WHICH ADDED VALUE WILL PARTNER BRING IN THE FIELD OF PUBLIC HEALTH?

The strategic value of PARTNER is based on the European wide gathering of information on treatment of VRT and the provision of this information to experts generating new guidance recommendations for daily practice for use by ERN and non-ERN Institutions.

The proposed tasks and milestones will increase the collaboration amongst member states in paediatric oncology and will be able to include also LHEAR (Low Health Expenditure Average Rate) countries in the process. This project will result in a platform for VRT that could represent a model for a comprehensive approach (case registration, international case consultation and treatment recommendations, website to give parents/patients information) in the field of rare diseases.

PARTNER will establish a registry linked with a virtual consultation system that will increase the capability of acquiring further significant knowledge and give expert advice to clinicians. According to the strategy of the EU cross border directive, this project will promote the “travelling” of knowledge and expertise across Europe.

Innovation will be embedded in the new platform: innovative IT tools will link the existing databases with the help of the EUPID system assuring interoperability and anonymisation of patients’ data. This may serve as a model for data set integration at the EU level thus paving the way for integration of registries in the near future across the globe. This project builds upon work and actions from the EU-funded ENCCA and ExPO-r-Net projects. The information collected and tools developed will be disseminated to key stakeholders (other ERN, European Clinical Trials Groups, parents and patients) to enhance further collaborations.

TARGET GROUPS

- **Patients and their families:**
patients’ association will benefit from an international network that can give advice and may reduce or even avoid in principle patients/families travelling in search for expert care
- **Paediatric oncology centres with low expertise in VRT:**
clinicians will benefit from a dedicated platform including data registration, expert clinical advice and clinical recommendations
- **National healthcare systems:**
patients will be treated according international standards thus benefiting from this European effort

WHY?

- **Very Rare Tumours (VRT) are still an orphan disease in Europe**
- **A European registry is a step further on the way to ameliorate the care of VRT patients**
- **Data collection may contribute to optimised consultation of patients with VRTs**
- **Experts want to increase clinical research and knowledge**

HOW?

- **Identification of the VRT entities**
- **Selection of a core of variables**
- **Use of common definitions**
- **Implementation of harmonised procedures for data collection, data quality control and central review**



Partner

Paediatric Rare Tumours
Network - European Registry



If you work on frequent cancers, do randomised trials! If you work on rare cancers – Find friends!



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