

# Partner

Paediatric Rare Tumours  
Network - European Registry



## ERN-PAEDCAN Partner: Paediatric Rare Tumours Network – European Registry

Improving the care of children with rare cancer through collaboration

### WHAT?

PARTNER is a 3-year long project part of the European Reference Network for Paediatric Cancer (ERN PaedCan). It aims to create a Paediatric Rare Tumour European Registry dedicated to children and adolescents with VRT (Very Rare Tumours) linking existing national registries and to provide a registry for those countries not already having a registry for VRT in place.

### ADVANTAGES:

- No need for new national structures because the national registries will continue their activities using the already established structures
- Optimization of economic resources because national registries are using national resources and EU resources will be reserved to the international component of the registry
- Reduction of the administrative burden because each national registry will be compliant with the national regulations
- Easier and better quality of data collection from hospitals because the national language can be used for primary source data documentation and verification
- Possibility to link data with national biobanks
- Possibility to link with the future EU proposed IT ERN platform

### WHY?

During the last years the European paediatric oncology community has increasingly recognized the necessity to develop projects dedicated specifically to rare paediatric tumours to overcome all these obstacles.

Malignant tumours are rare disease in children with an annual incidence rate of 12,7 new cases per 100.000 children per year in Europe. They are constituted by a wide spectrum of different histologies with various clinical and biological characteristics. Leukaemia and cerebral tumours are the most frequent diagnosis followed by less common entities. There is a group of paediatric very rare tumours (VRT), which is extremely heterogeneous. Some VRT characteristically arise at the paediatric age, such as pleuropulmonary blastoma or pancreatoblastoma. Other tumours more commonly develop during adulthood or may even be frequent in adult patients (i.e. colon cancer or malignant melanoma) but they only rarely develop in children and adolescents. There is growing evidence that at least some of them are biologically

and clinically distinct from their adult counterpart. Last, a substantial group of “borderline” tumours with uncertain clinical behaviour and no standard treatments are usually also included in the group of VRT.

### HOW?

The strategic value of PARTNER in the field of public health 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 collection of data will contribute to optimised consultation of patients with VRTs. Consequently, experts will increase clinical research and knowledge.

- 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 is an interoperable  
Model concept for integrated  
IT solution for ERNS**

## WHO?

### COORDINATOR

- Azienda Ospedaliera di Padova (Italy)

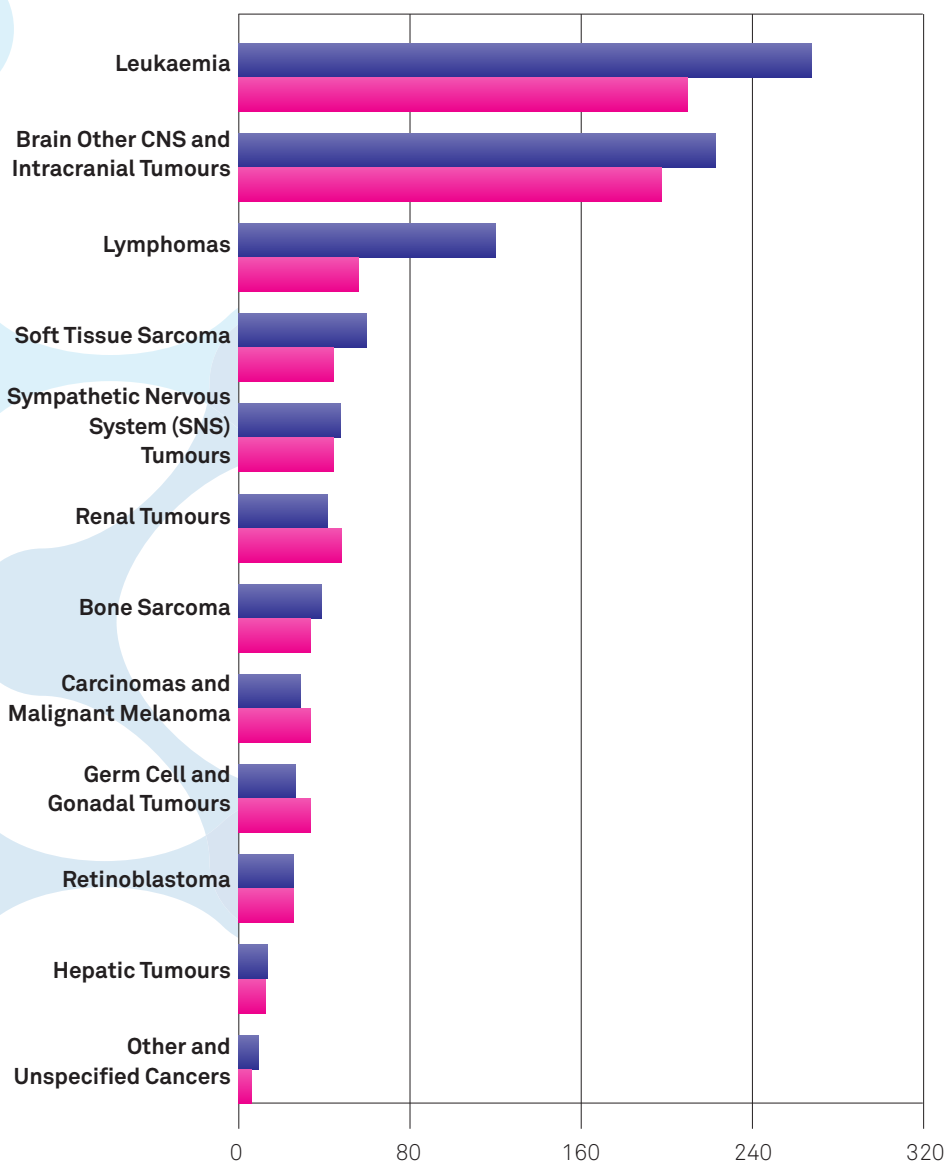
### ASSOCIATED PARTNERS

- St. Anna Kinderkrebsforschung (Austria)
- Klinikum Dortmund gGmbH (Germany)
- Eberhard Karls Universitaet Tuebingen (Germany)
- Institut Curie (France)
- Gdanski Uniwersytet Medyczny (Poland)

### COLLABORATING STAKEHOLDERS

- Istituto Nazionale per la Cura dei Tumori (Italy)
- Royal Manchester Children's Hospital (United Kingdom)
- Hospital Universitario Cruces (Spain)
- University Medical Centre (Slovenia)
- Clinical Hospital Centre (Croatia)
- University Children Hospital (Slovakia)
- University Hospital Santariskiu Klinikos (Lithuania)
- University Children's Hospital (FYR Macedonia)
- Hospital Luis Calvo Mackenna (Chile)
- Sahlgrenska University Hospital (Sweden)
- Hellenic Society Pediatric Haematology Oncology (Greece)
- Childhood Cancer International Europe (Austria)
- CHU de Saint Denis (La Réunion - France)
- Hadassah University Hospital (Israel)
- Marciniak Hospital (Poland)
- Institute of Oncology (Romania)
- Institutul Oncologic "Ion Chiricuta" (Romania)
- University Children Hospital (Serbia)

AVERAGE NUMBER OF CASES PER YEAR •Boys •Girls



If you work on frequent cancers,  
do randomised trials!

If you work on rare cancers,  
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