

REVIEW

The challenge of very rare childhood cancers in developed and developing countries

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ABSTRACT

Introduction: The improvements made in the field of pediatric oncology in the last decades due to the propensity to develop national and international cooperative protocols have not been historically seen for a number of very rare pediatric neoplasms whose common denominator lies in their having been treated as orphan diseases. For several years now, this situation has fortunately been gradually changing, and various projects dedicated to these rare diseases have been developed in several countries.

Areas covered: This paper describes the schemes dedicated to rare pediatric tumors in countries with different development levels, with a particular reference to the EXPeRT (European Cooperative Study Group for Pediatric Rare Tumors) project.

Expert opinion: Experience gained in recent years on rare tumors in childhood underscores the importance of cooperation and networking. Further efforts are now needed to extend research and improve the quality of patients care. The pediatric study groups that have invested their resources in this area must now strive to obtain institutional recognition and to seek new partnerships with adult medical oncology centers, organizations concerned with biological-genetic studies, and partners such as pharmaceutical industries, regulatory authorities, and international funding commissions.

The involvement in the **ExPO-r-Net** project (European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment) have given to the EXPeRT the necessary support to implement its activities, and in particular to develop a specific website to inform the non-scientific community and to set up a virtual tumor board and advisory desk for professionals.