

Rare Cancers in Children – The EXPeRT Initiative: A Report from the European Cooperative Study Group on Pediatric Rare Tumors

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In 2008, EXPeRT (European Cooperative Study Group for Pediatric Rare Tumors) was founded by national groups from Italy, France, United Kingdom, Poland and Germany.

The first aims of EXPeRT were to agree on a uniform definition of VRTs and to develop the currently most relevant scientific questions.

Current initiatives include international data exchange, retrospective and prospective studies of specific entities, and the development of harmonized and internationally recognized guidelines.

Moreover, EXPeRT established a network for expert consultation to assist in clinical decision in VRTs.

Table 1: Registration of very rare tumors to the different European national rare tumor groups and spectrum of tumors evaluated within the EXPeRT initiative.

Selected VRT-Entity	France	Germany	Italy	Poland	U.K.	EXPeRT
nasopharyngeal carcinoma		NPC				
salivary gland tumors		STEP				
other ENT tumors		MET				
thyroid cancer						
breast cancer, other breast tumors						
thymoma		STEP				
mesothelioma	FRACTURE		TREP			
pleuropulmonary blastoma				PPRTSG	NRCT	EXPeRT
bronchial carcinoma		CWS				
carcinoids, other endocrine cancers		STEP				
adrenocortical carcinoma		MET				
pheochromocytoma and paraganglioma						
renal cell carcinoma	SIOP Wilms Study	STEP/SIOP Wilms Study	TREP/AIEOP Wilms Study			
rhabdoid tumors	EpSSG	EURO-Rhabdo CWS/Wilms/HIT	EpSSG	CWS	EpSSG	
pancreatic tumors, pancreatoblastoma						
gastrointestinal carcinomas	FRACTURE	STEP				
GIST		CWS	TREP	PPRTSG	NRCT	EXPeRT
stromal and epithelial gonadal tumors	TGM	MAKEI/STEP				
rare mesenchymal tumors	EpSSG	CWS	EpSSG	CWS	EpSSG	
melanoma incl. variants						
other carcinomas	FRACTURE	STEP	TREP	PPRTSG	NRCT	EXPeRT
others						

FRACTURE, groupe FRAnCais des Tumeurs Rares de l'Enfant; TGM, germ cell tumor protocol; TREP, Tumori Rari in Età Pediatrica; STEP, seltene Tumoren in der Pädiatrie; MET, Malignant Endocrine Tumors; NPC, Nasopharyngeal Carcinoma Registry; MAKEI, Malignant Germ Cell Tumor Trial; CWS, Cooperative Soft Tissue Sarcoma Study; HIT, Childhood Brain Tumor Network; PPRTSG, Polish Paediatric Rare Tumours Study Group; NRCT, UK National Registry of Childhood Tumours