Joining forces for pediatric very rare tumors

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The EXPeRT was established in 2008 by the national Very Rare Tumors (VRTs) working groups from Italy, France, Germany, Poland, and the United Kingdom, its stated aim being to improve the available treatments and promote research in the relatively uncharted territory of pediatric VRTs.

The EXPeRT’s founding members had several things on their wish list: (1) to pool national retrospective series of specific tumor types to obtain large series enough to enable treatment-related risk stratification and generate homogeneous therapeutic recommendations, a shared research methodology, and a common framework; (2) to develop an organization with the double purpose of promoting research and serving as an advisory network to help with difficult decisions regarding single clinical cases; and (3) to set up an international prospective case registry.

The promotion of research on pediatric VRT (and thereby improving the prognosis of affected patients) is a challenging endeavor. It demands the input of new ideas and the activation of new partnerships every step of the way. The only solution is to join forces, pool our resources, boost our collaborative efforts, involve everyone working on pediatric VRTs, be they international experts, specialists in various fields, care providers, families and patients, regulators, or providers of funding. We also need to work in synergy with the adult oncology community, for which our pediatric collaborative experience may serve as a helpful organizational model.