

Abstract

The SIOP European Neuroblastoma Research Network (SIOPEN-R-NET) aims to optimise the use of European pre-existing infrastructures in the individual countries and to improve their consistency and complementarity on a European level. The pooling of data will contribute to harmonised standard procedures and integrate the research efforts to reach a critical mass.

The SIOPEN-R-NET will utilize the Internet and a WEB based central database to form a virtual research community to ultimately improve the survival in children with neuroblastoma.

A European high-risk neuroblastoma treatment protocol will establish superior treatment approaches. A virtual tumour bank will allow biological studies to identify further prognostic parameters. Central serum banking will in turn allow pharmacokinetic studies to correlate drug levels with optimum dosing in view of efficacy (survival) and toxicity (morbidity, mortality) and to perform immunological monitoring.

The SIOPEN-R-NET will co-ordinate prospective multinational risk adapted trials and be the basis to exchange the experience acquired, to disseminate results and to inform users.

The SIOPEN-NET

... will be based on the Internet and a Web accessible central database and communication system to allow clinical trial management with remote data entry on electronic case report forms (eCRFs), electronic data capture, remote randomisation and the distribution of information on trial progress.

... will develop a large scale European high-risk study and establish common European standards in the clinical and research field.

... will build and manage a research network for joint data gathering and /or experiments to improve Europe-wide quality by using adequate preparation, exchange and circulation of reference material, built up material resources and repositories needed for research work.

... will establish the first European Neuroblastoma tumour bank allowing basic research being competitive world-wide and help to identify and describe biological risk factors as initiated by the ENQUA project (European Neuroblastoma Quality Assessment project). By improving disease evaluation, it will establish new diagnostic tests and procedures aiming at detecting early markers and weak signals in pathology, including nucleic acid diagnostic tests, and in vivo imaging.

... will foster Europe-wide reference assessment and central quality controls to allow new insight into disease response dynamics and a better understanding of minimal metastatic residual disease causing fatal disease recurrence. Guided drug dosing will be introduced to increase drug efficacy to lower toxicity seeking risk adapted treatment intensity, which is directly related to life quality. Immunoresponse will be monitored and correlated with clinical outcome.

... will help to improve the quality and user-orientation of these research services to the European research community but also to parent association of families with children suffering from neuroblastoma.