ERN on genetic tumour risk syndromes (ERN GENTURIS)

Genetic tumour risk syndromes are disorders in which inherited genetic mutations strongly predispose individuals to the development of tumours. The lifetime risk of cancer can be as high as 100 %. While there is considerable diversity in the organ systems that may be affected, individuals affected by these conditions share similar challenges: delay in diagnosis, lack of prevention for patients and healthy relatives, and therapeutic mismanagement. At present, only 20-30 % of people with genetic tumour risk syndromes have been diagnosed.

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ERN GENTURIS is working to improve identification of these syndromes, minimise variation in clinical outcomes, design and implement guidelines, develop registries and biobanks, support research, and empower patients. The network will educate the public and healthcare professionals, and foster the sharing of best practice across Europe. Access to multidisciplinary care will be improved, with new models and standards for sharing and discussing complex cases. The network is enhancing the quality and interpretation of genetic testing, and increasing patient participation in clinical research programmes.

ERN GENTURIS will cooperate with other ERNs to improve the care of patients with genetic tumour risk syndromes who develop conditions that fall within the expertise of another network.

NETWORK COORDINATOR

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