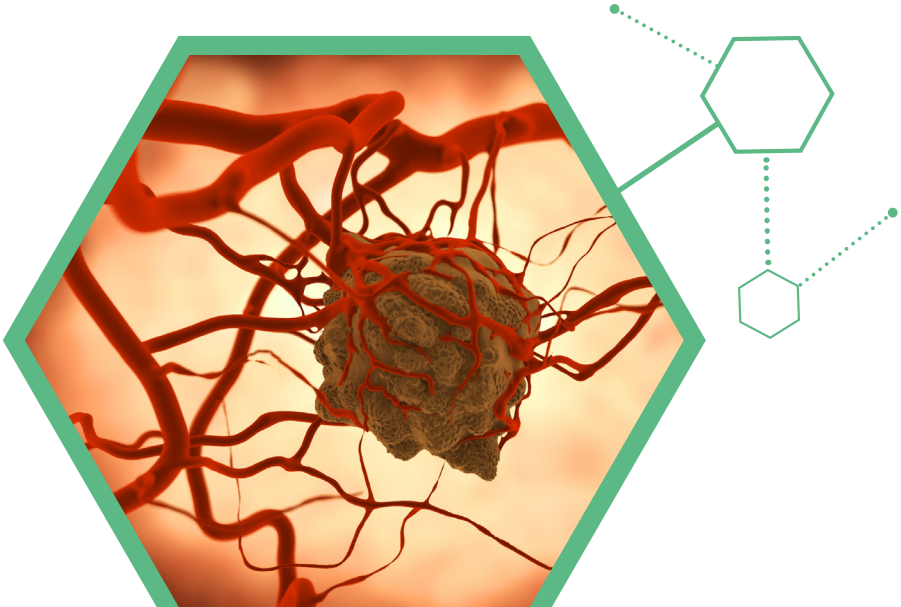
ERN on genetic tumour risk syndromes (ERN GENTURIS)

Genetic tumour risk syndromes are disorders in which inherited genetic variants strongly predispose individuals to the development of tumours. The lifetime risk of cancer can be as high as 100 percent. 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 a small minority of people with genetic tumour risk syndromes has been diagnosed as such.

ERN GENTURIS is working to improve identification of these syndromes; minimise variation in clinical outcomes; design and implement EU-guideline; develop the GENTURIS registry; support research; and empower patients. The network educates the public and healthcare professionals via its website, by organising regular webinars and courses, and by fostering sharing of best practice across Europe. Both virtual and face-to-face access to multidisciplinary care will be improved, in order to share and discuss complex cases. The network is enhancing the quality and interpretation of genetic testing and increasing patient participation in clinical research programmes.

ERN GENTURIS cooperates 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.



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