

ERN GENTURIS

European Reference Network on Genetic Tumour Risk Syndromes



Coordinator: Nicoline Hoogerbrugge, MD, PhD

Radboud university medical center, Department of Human Genetics 836, Nijmegen, The Netherlands



Background

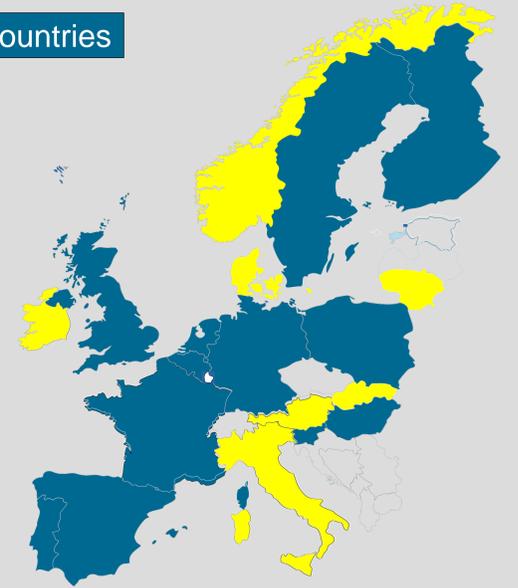
- ❖ Patients with Genetic Tumour Risk Syndromes (genturis) are at very high risk to develop tumours in multiple organ systems at a relatively young age.
- ❖ There are more than 40 different genturis.
- ❖ Hereditary tumours often look like common tumours, but behave differently and need a different approach in detection and treatment.
- ❖ Patients and their relatives deal with psychosocial issues related to hereditary diseases or to syndrome-specific issues.
- ❖ For all patients with genturis a personalized treatment, based on their germline mutation, is essential.
- ❖ Also healthy relatives should receive proper medical management in order to give optimal genetic and social counselling and prevent tumours.

HCP members

23 endorsed HCP in 12 countries

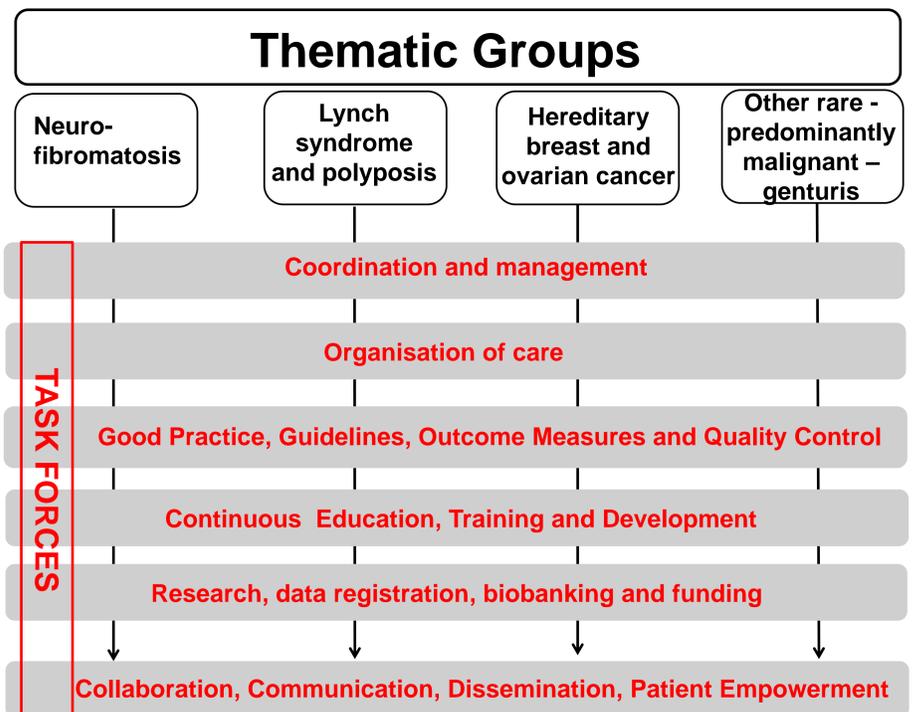
Endorsement in 2017?

No member yet

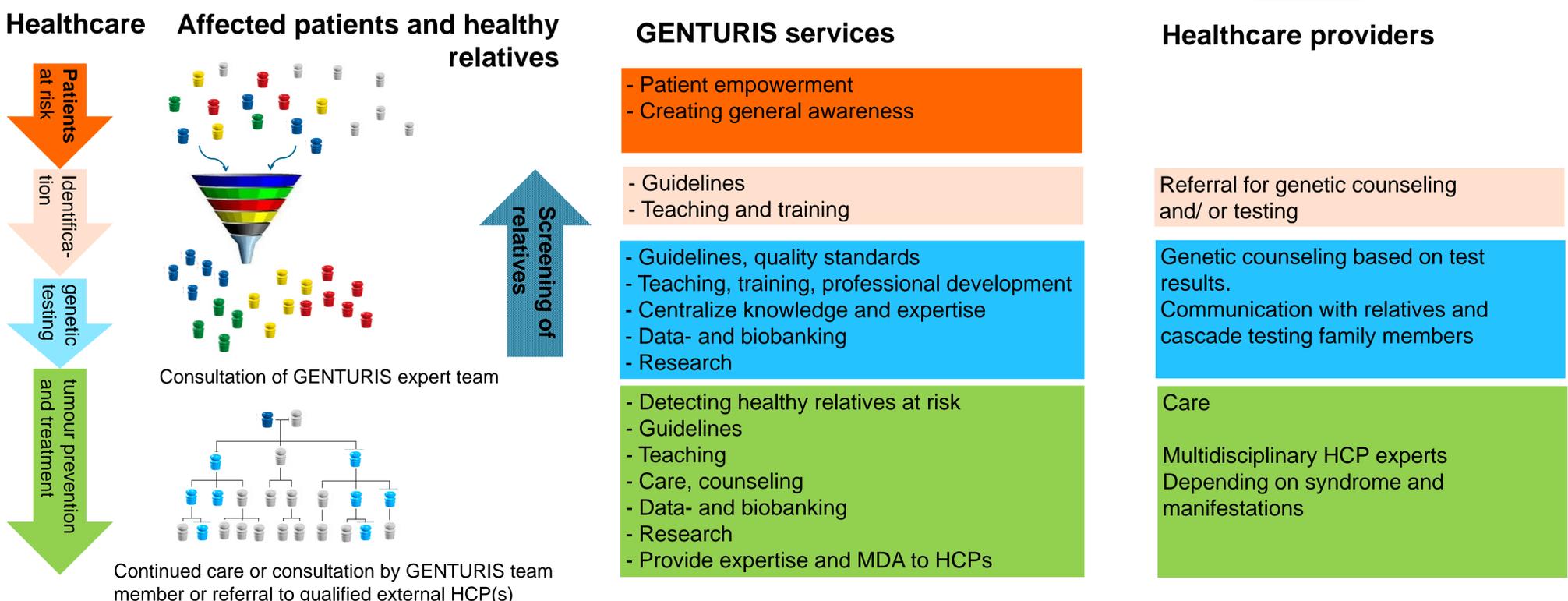


Aims of ERN GENTURIS

- ❖ Improved identification of people living with a genturis
- ❖ Reduced variation in clinical practice and outcomes
- ❖ Development of evidence based clinical guidelines
- ❖ Development and use of patient registries, biobanks and research projects
- ❖ Defined health care pathways to facilitate improved access to international specialist clinical knowledge for patients and their families living throughout the EU
- ❖ Pan-European development and use of patient registries, biobanks and research studies
- ❖ Giving a home to all people with a genturis



GENTURIS patient care pathway and related services provided



Contact:
genturis@radboudumc.nl

More information:
www.genturis.eu

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