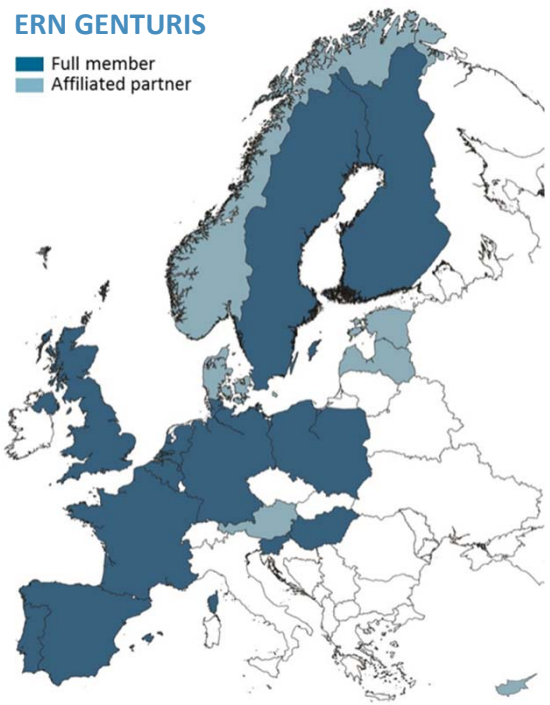
The GENTURIS registry enables sharing of knowledge and resources from expertise centers across Europe to improve **diagnostics, treatment and prevention** of cancer in patients with genetic tumour risk syndromes.

- **> 25 specialist healthcare providers**
- **> 42000 genturis patients**

ERN GENTURIS



CONTACT

GENTURIS registry project representatives

Radboud university medical center
Department of Genetics
- Prof. dr. Nicoline Hoogerbrugge
- Dr. Janet Vos

University Medical Center Groningen
Genomics Coordination Center
- Prof. Dr. Morris Swertz
- Prof. Dr. Rolf Sijmons

For more information about the GENTURIS registry and ERN GENTURIS

Visit our registry website:
https://genturis-registry.eu

Visit the ERN GENTURIS website:
https://www.genturis.eu

This leaflet was funded by the European Union's Health Programme (2014-2020).

Publication date: 29/07/2020

GENTURIS registry

GENTURIS registry

European Reference Network
for rare or low prevalence complex diseases

Network Genetic Tumour Risk Syndromes (ERN GENTURIS)

www.genturis.eu

European Reference Network (ERN)

European Reference Networks (ERNs) are virtual networks of healthcare providers from **expertise centers all over Europe**. ERNs aim to improve the care of patients with a rare or complex disease for which high specialized treatment and shared knowledge and resources are needed.

- > 40 different genturis
- 70-80% not yet diagnosed

ERN GENTURIS

ERN GENTURIS is the European Reference Network for all patients with **a genetic tumour risk syndrome** (GENTURIS). The network aims to improve **diagnostics, treatment and prevention** of cancer in patients with genetic tumour risk syndromes trough care, guideline, research and educational activities. ERN GENTURIS covers genetic tumour risk syndromes in four thematic disease groups:

1. Neurofibromatosis
(NF1, NF2, Schwannomatosis)

2. Lynch Syndrome and Polyposis
(e.g. FAP, MAP, PPAP, NAP, Peutz-Jeghers)

3. Hereditary Breast and Ovarian Cancer
(e.g. BRCA1, BRCA2, ATM, PALB2, CHEK2)

4. More rare and predominantly malignant genetic tumour risk syndromes
(e.g. PHTS, Li-Fraumeni, Birt-Hogg-Dubé, FAMMM, CDH1 related HDGC)

GENTURIS registry

The GENTURIS registry is a web-based platform that facilitates standardized data registration and sharing of data across Europe, to optimize detection, treatment and prevention of cancer in patients with genturis.
The registry includes both **general data and disease-specific data** for all thematic disease groups covered by ERN GENTURIS.

By design, the registry complies with the legal, ethical and privacy standards required within Europe, while facilitating the sharing of data which is essential to answer questions on rare diseases.
To accelerate new knowledge of genetic tumour risk syndromes, the registry enables a new wave of research opportunities from translational to epidemiological studies to clinical trials.