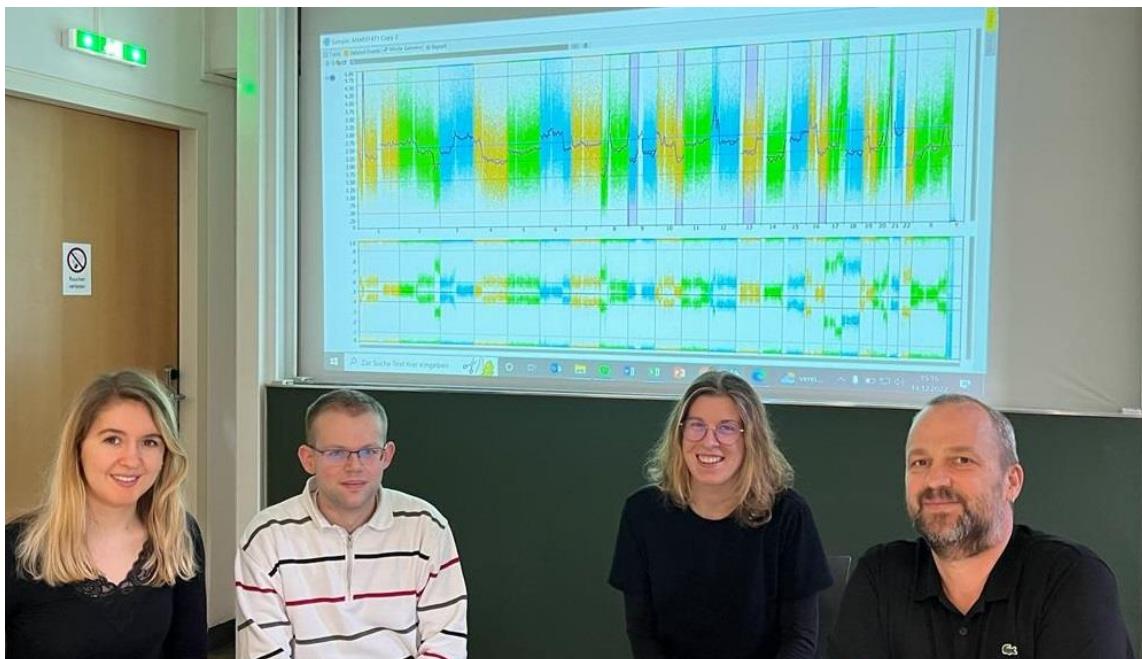


Newsletter February 2023

Successful ERN GENTURIS exchange visits

The EC ERN Exchange Programme, funded via HaDEA and facilitated by Ecorys, closed to applications on 31 December 2022. ERN GENTURIS arranged 16 exchanges, successfully increasing knowledge sharing across the network. The last two exchanges took place in December:

[Vita Setrajcic Dragos and Aleksander Novakovic from the Institute of Oncology in Ljubljana](#) visited the [Institute for Human Genetics in Innsbruck](#). Katharina Wimmer, Simon Schnaiter and their colleagues gave the visitors hands-on training on homologous recombination deficiency (HRD) analysis and interpreting SNP-Array data.



From left to right: visitors Vita and Aleksander, and hosts Juliane and Simon.

[Maria Haanpää from Turku University Hospital](#) visited the [Netherlands Cancer Institute \(NKI\) in Amsterdam](#). The hosts Irma van de Beek and Monique van Leerdam showed how genetic testing, patient flow and multidisciplinary team collaboration works in a large setting.



From left to right: Maria Haanpää, Irma van de Beek and NKI colleagues.

ERN GENTURIS would like to thank all its visitors and hosts for their enthusiasm and dedication!



European
Reference
Networks



European
Reference
Network
for rare or low prevalence
complex diseases
Network
Genetic Tumour Risk
Syndromes (ERN GENTURIS)



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ERN GENTURIS TUMOUR MANAGEMENT IN NEUROFIBROMATOSIS TYPE 1 GUIDELINE

Publication date 18 January 2023

Authors: Charlotte Carton, D. Gareth Evans, Ignacio Blanco, Reinhard E. Friedrich, Rosalie E. Ferner, Said Farschtschi, Hector Salvador Hernandez, Neurofibromatosis Type 1 Guideline Group*, Amedeo A. Azizi, Victor Mautner, Eric Legius, Claas Röhl, Sirkku Peltonen, Stavros Stivaros, and Rianne Oostenbrink

The new ERN GENTURIS NF1 guideline publication is online in EClinicalMedicine: <https://doi.org/10.1016/j.eclinm.2022.101818>

The recently guideline publication as well as the complete guideline and the pocket guide can be found on the ERN GENTURIS website: <https://www.genturis.eu/l=eng/Guidelines-and-pathways/Clinical-practice-guidelines.html>



Upcoming EJP RD workshops by ERN GENTURIS members

In the context of EJP RD's ERN Workshops, ERN GENTURIS members organise the following upcoming workshops:

- **Psychological, molecular and administration aspects of Hereditary breast and ovarian cancer genetic population screening (HBOC GPS)**, by Arvids Irmejs.
27-28 April 2023 (Riga, Latvia), registration deadline: 22 February, more information [here](#)
- **Desmoid tumors (DTs) in patients with Familial Adenomatous Polyposis (FAP): an interdisciplinary approach**; by Marco Vitellarro.
22-23 May 2023 (Milano, Italy). Registration deadline 7 March. More information [here](#)





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Editorial

European collaboration on genetic tumour risk syndromes

[Hildegunn H. Vetti](#)¹  , [Ignacio Blanco](#)², [Fred H. Menko](#)³

With the publication of the Editorial paper "[European collaboration on genetic tumour risk syndromes](#)" by Hildegunn H. Vetti, Ignacio Blanco and Fred H. Menko, the **ERN GENTURIS special issue of the European Journal of Medical Genetics** is now complete, containing 13 publications by ERN GENTURIS members! Click [here](https://www.sciencedirect.com/journal/european-journal-of-medical-genetics/special-issue/10PFC6MB478) for the complete special issue: <https://www.sciencedirect.com/journal/european-journal-of-medical-genetics/special-issue/10PFC6MB478>



GENTURIS
registry

First 100 patients enrolled in the GENTURIS registry

On 7 February the GENTURIS registry reached an important milestone: the first 100 patients were enrolled! Soon the interactive dashboard will go live providing you with a real-time snapshot of the GENTURIS registry enrolment.

For more information about the GENTURIS registry, see <https://genturis-registry.eu/>

Upcoming ERN GENTURIS webinars

08-03-2023

Richarda de Voer

[Genetics of \(new\) colorectal cancer & polyposis syndromes](#)

22-3-2023

Marco Vitellaro

[Familial adenomatous polyposis - the surgeon's perspective](#)

For more information and registration, visit www.genturis.eu

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