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ERN GENTURIS
Newsletter

European Reference Network | Genetic Tumour Risk Syndromes (ERN GENTURIS)

September 2025

ERN GENTURIS news

ERN GENTURIS Podcast

We are excited to launch the very first episode of **the ERN GENTURIS podcast - GENTURIS Genes**!

This new podcast series is dedicated to raising awareness and sharing expert knowledge on genetic tumour risk syndromes.

In our debut episode, our guests **Prof. Marjolijn Ligtenberg**, Coordinator of ERN GENTURIS and **Liliana Sousa**, chair of our Communication Task Force, will explore what hereditary cancer means, why it matters to both patients and clinicians, and how informed decisions about genetic counselling can change healthcare outcomes.

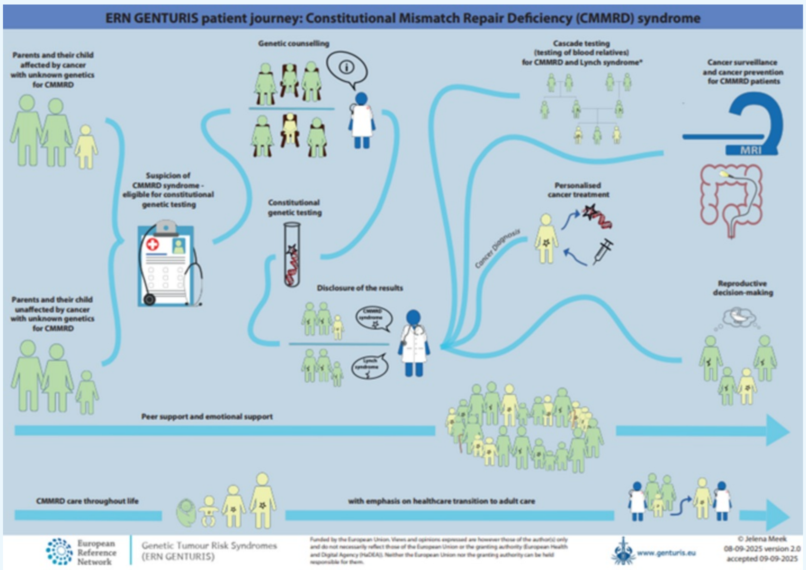
Whether you're a healthcare professional, researcher, patient, or simply curious about inherited cancer risks, this podcast is for you.

Big thanks to Mikk Tooming, Megan Eckley and the entire Task Force 6 for their involvement in production of the Podcast.

Listen now and follow the series to stay informed!

spotify

Patient Journey CMMRD



The newly published CMMRD (Constitutional Mismatch Repair Deficiency) Patient Journey is now available on our website.

Understanding this journey is crucial for improving diagnosis, treatment, and support for those affected by CMMRD.

Constitutional Mismatch Repair Deficiency is an extremely rare genetic condition (1 in 1,000,000 new-borns) that causes an increased risk for a broad tumour spectrum including brain tumours, haematological malignancies and colorectal cancers, already in children and young adults. The cancer risk in CMMRD is one of the highest among childhood cancer syndromes (>90% at age 20), with a mean age at first tumour of 7.5 years.

A big thank you to everyone who contributed to making this Patient Journey possible, especially the CMMRD guideline group and Manon Engels.

patient journeys

ERN GENTURIS LinkedIn

We’ve reached 1,000 Followers on ERN GENTURIS LinkedIn!
Thank you to every one of you for being part of our community. Your support helps us amplify our mission to improve the lives of patients with Genetic Tumour Risk Syndromes (ERN GENTURIS).

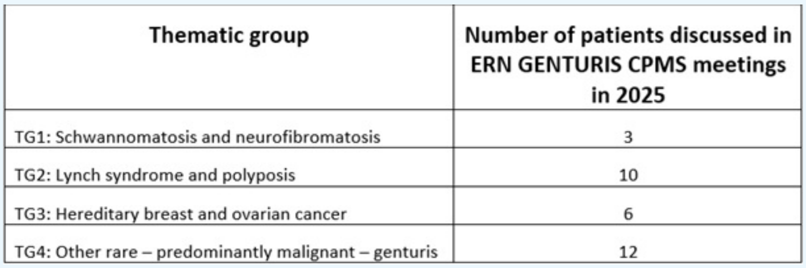
If you're not yet following us, now is a great time to join! Follow our page to stay updated on:

- New tools and guidelines for healthcare professionals.
- Webinars, events, and training opportunities.
- Patient stories and advocacy efforts.
- The latest advances in research and clinical care.

Let's keep building this network and working together to make a difference.

linkedin

ERN GENTURIS CPMS news



Thematic group	Number of patients discussed in ERN GENTURIS CPMS meetings in 2025
TG1: Schwannomatosis and neurofibromatosis	3
TG2: Lynch syndrome and polyposis	10
TG3: Hereditary breast and ovarian cancer	6
TG4: Other rare – predominantly malignant – genturis	12

ERN GENTURIS overview of patients in 2025

In the discussions organized through the Clinical Patient Management System (CPMS 2.0), ERN GENTURIS has provided tailored expert advice to **31** genturis patients and their families in 2025 so far.
For more information on how to refer a patient for discussion in an ERN GENTURIS CPMS meeting and how to use the CPMS, please see:

- How to refer a patient
- CPMS information and policy
- Guides on how to use CPMS 2.0

CPMS 2.0 information for members

CPMS upcoming change to expertise system

To ensure that our experts can be found based on specific expertise, we have submitted a request to change thematic and subthematic areas to allow more specific expertise to be indicated in the CPMS. However, the thematic/subthematic areas in the CPMS are currently directly linked to the thematic/subthematic areas that have been officially recognised by the EC and approved by the Board of Member States (BoMS). Based on feedback from multiple ERNs, the CPMS support team will update the CPMS to uncouple the officially recognised thematic/subthematic areas from the expertise areas that can be indicated in the CPMS so that these can easily be changed as needed without a requirement for additional approval from the BoMS.

We have also requested an expansion of the number of characters allowed in the text field that allows experts to describe their own expertise in more detail (current limit ~300 characters, requested limit ~1500 characters).

For details on how to indicate your expertise in the CPMS, please see our CPMS 2.0 guide to indicating expertise.

CPMS meeting connectivity issues

Several of our members have experienced problems connecting to our CPMS recurring meetings using the CPMS 2.0 built-in video conferencing tool. As these connectivity problems are almost exclusively related to the firewall settings of the institute that the user is trying to connect from, it can usually be solved by switching to a different internet connection. For more permanent potential solutions to connectivity issues, please see below.

If you are experiencing connectivity issues please notify our CPMS helpdesk manager, Jurriaan Hölzenspies.

A troubleshooting guide for CPMS meeting connectivity issues is available on the genturis website on our CPMS guides and videos page.

Education opportunities

ERN GENTURIS educational webinars

24 September 2025
APC mosaicism and panel testing depending on polyp count
Maartje Nielsen

08 October 2025
Heritable retinoblastoma – long-term follow-up and care
Pernille Axél Gregersen

12 November 2025
Hereditary childhood cancer
Marjolijn Jongmans

10 December 2025
DICER1-associated thyroid tumours - the pathologist’s perspective
Giovanni Tallini

Watch the previous webinars here:

webinars

General news

EU budget proposal for the years 2028-2034

The European Commission (EC) published on 16 July 2025 a draft proposal for the EU Budget 2028-2034 — a key document shaping the future of Europe’s priorities.

One of the most notable changes? **There will no longer be a dedicated Health Programme budget**. The EU4Health programme, previously a standalone initiative, is now subsumed under the newly proposed European Competitiveness Fund (ECF).

The European Commission has opened a public consultation and is collecting feedback until **5 November 2025**. All feedback received will be summarised by the Commission and presented to the European Parliament and the Council, with the aim of contributing to the legislative debate.

consultation

Funding opportunities

European Commission Calls

- HaDEA Calls for **Proposals on Health**
- HaDEA Calls for **Tenders on Health**
- Horizon Europe calls for **Funding on Health**
- **EC Health calls**

Upcoming Meetings & Events

European Hereditary Tumour Group meeting in Heidelberg

The 9th Annual EHTG Meeting will take place on 19-21 September 2025, in Heidelberg, Germany.

The internationally recognized speakers, including members of ERN GENTURIS and patient representative (Georgina Hoffmann) are going to present their work.

The EHTG 2025 meeting will provide a broad forum on hereditary tumor syndromes, covering advances in genetics, prevention, clinical management, and emerging therapies. An exciting program including debates, planel discussions, patient perspectives and keynote talks will provide ample opportunities for interdisciplinary exchange and new collaborations.

ERN GENTURIS members will present their work during the EHTG 2025 meeting and on Sunday, September 21th at 14:30 CET Katharina Wimmer and Chrystelle Colas will present **ERN GENTURIS Guidelines**.

One day before the EHTG 2025 Meeting, the Satellite Symposium on Tumors with Microsatellite Instability will take place at the same venue. Laura Valle, a member of ERN GENTURIS, will be one of the speakers.

For more information on the EHTG please visit website:

website

Workshop on patient rights

The next workshops on Patients' Rights and Rare Diseases in the European Union will be organised by the Czech Republic and the

Netherlands and Germany.

- The workshop organised by Czech Republic, will be held in Prague on 26 September 2025. Working language will be in Czech with translation available in English.
  Please register through the following link.
- The workshop organised by the Netherlands and Germany, will be held in Groningen, the Netherlands on 30 October 2025. Working language will be in English with translation available in Dutch and German. Please register through the following link.

More details and the agendas of the events are available on the registration website.

FAIR Training Program for Rare Disease Research, 24-26 September

The FAIR Training Program is now open for registration. The online event is jointly organised by ERDERA and their associated partners and hosted by the World Duchenne Organization. The FAIR Training Program 2025 – 2027 falls under the framework of ERDERA and aims to equip participants with theoretical understanding and practical tools for implementing the FAIR data principles – Findability, Accessibility, Interoperability, and Reusability – in the context of health research and rare diseases.
This training event is part of a series of three annual training opportunities to master FAIR principles in practice.

The first event will take place online from **24 to 26 September 2025, with daily sessions scheduled between 13:30 and 17:00 CET.**

more information

ERN GENTURIS annual meeting 2025

SAVE THE DATE: The next ERN GENTURIS annual meeting will take place on 27 and 28 November 2025 in Amsterdam, the Netherlands.
The meeting will start at 09.00 on Thursday and will end at 17.00 PM on Friday.
The meeting venue is the same as in previous years and located at one of the most beautiful canals in the centre of Amsterdam: The Trippenhuis (Royal Dutch Academy of Science).

High-Level Meeting on a European Research and Innovation Ecosystem for Rare Diseases

SAVE THE DATE: High-Level Meeting (HLM) on a European research and innovation ecosystem for rare disease, is scheduled on December 9-11, 2025, in Brussels, Belgium.

Visit our:
Website and LinkedIn

ERN GENTURIS
With every diagnosis we can help an entire family