ERN GENTURIS Newsletter

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

June 2025

ERN GENTURIS news

ERN GENTURIS publications

New Publications:

1. The risk of a second primary cancer in PTEN Hamartoma Tumor Syndrome (PHTS), by Linda A.J. Hendricks & Katja C.J. Verbeek, et al., May 2025, Genetics in Medicine
2. Cancer prognosis and treatment results in patients with PTEN Hamartoma Tumour Syndrome (PHTS) – a European cohort study, Linda A.J. Hendricks, et al., June 2025, BJC Reports.

publications

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	6
TG3: Hereditary breast and ovarian cancer	1
TG4: Other rare – predominantly malignant – genturis	5

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 22 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 recurring meeting connectivity

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 for 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.

CPMS mobile app now available in Google and Apple app stores

The CPMS 2.0 Mobile App was released last week (June, 19) and is now available in the Android and Apple app stores as "EU CPMS 2.0":

- Android
- Apple

The app was tested by the ERN helpdesks in the monthly helpdesks meeting and everything seemed to be working very well, including the audio and video functionality in CPMS meetings. The app is very easy to use and simplifies the login process as the CPMS app automatically interfaces with your EU login app to facilitate login.

If you decide to try the app, we would highly appreciate any feedback you can give (positive or negative). If you have any feedback after using the app, please send it to our CPMS helpdesk manager, Jurriaan Hölzenspies.

ERN Coordinators meeting in Rome

On 21 May 2025, the 22nd meeting of the ERN Coordinators Group with DG SANTE representatives, took place in Rome at the Italian Ministry of Health. This important gathering brought together coordinators and Project Managers from across the European Reference Networks to discuss several key points aimed at enhancing collaboration and patient care across Europe. ERN GENTURIS was represented by **Marjolijn Ligtenberg and Nicoline Geverink.**

The discussions focused on strengthening network coordination, sharing best practices, and advancing initiatives that support cross-border healthcare.

Lynch Syndrome Symposium

On 20 May 2025, the first Lynch Syndrome Symposium took place at the Stuttgart Clinic, bringing together experts, healthcare professionals, and advocates to focus on prevention, early detection, and treatment of Lynch Syndrome.

Our Patient Representative, Georgina Hoffmann, shared her personal journey with Lynch Syndrome and presented the work of ERN GENTURIS to a broader audience. Her dedication and advocacy continue to make a meaningful impact in raising awareness about ERN GENTURIS.

Education opportunities

ERN GENTURIS educational webinars

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

LEARN: MOOC Diagnosing Rare Diseases

Now open! A facilitation window for the MOOC Diagnosing Rare Diseases: from the Clinic to Research and back is open from Monday, May 12, until Friday, July 4.

During this period, experts and mentors will be available online to answer participants' questions and stimulate insightful discussions throughout the course.
This free online course, developed within the European Joint Programme on Rare Diseases (EJP RD), was co-created by ERN GENTURIS, ERN ITHACA, EURORDIS, and the Fondation Maladies Rares.
The MOOC explores key topics in the diagnosis of rare genetic diseases, including:

- The diagnostic process and types of genetic tests available
- Differences in patient pathways for rare genetic diseases
- Technological advances in diagnostic research
- The importance of collaborative studies and data sharing
- The impact of having (or lacking) a diagnosis on patients' lives
- The contribution of physiopathological and social science approaches in rare disease diagnostics

course

General news

ERDERA launched Networking Support Scheme (NSS)

ERDERA has launched a Networking Support Scheme (NSS) offering up to €30.000 to support transnational networking events with a clear rare disease or rare cancer research focus.

The events should promote knowledge sharing, research uptake and collaborations among clinicians, researchers, and patients/patient advocacy organizations, and should support greater inclusion of underrepresented countries (UCs).

For the purpose of the NSS call the list of UCs is the following: Bulgaria, Cyprus, Czechia, Estonia, Georgia, Greece, Hungary, Iceland, Latvia, Lithuania, Morocco, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, and Türkiye.

Events must include participants from at least three different eligible countries and may be held either in-person or in a hybrid format.

Involvement of Early Career Researchers, young students, and involvement of patient advocacy organizations is encouraged.

The NSS is a permanently open call from **May 2025 onward until funds are exhausted which is expected in April 2029**.

Applications can be submitted at any time but are reviewed in six-monthly collection rounds. **The first deadline is 7 October 2025.**

more information

ERDERA patient survey

ERDERA has launched a new online survey to explore how rare disease patient organisations can contribute to publicly funded research. It will be open until mid-July.

This survey has been co-created with patient organisations and will help shape better, more meaningful involvement in research.

Share with your networks – your voice matters in building stronger patient engagement across Europe!

more information

EU allocates €145.5 million to boost European cybersecurity, including for hospitals and healthcare providers

The European Commission is making available €145.5 million to empower small and medium-sized enterprises and public administrations in deploying cybersecurity solutions and adopting the results of cybersecurity research. For this purpose, the Commission has launched two calls for proposals.

The first call is part of the Digital Europe Programme, with a budget of €55 million. €30 million of this amount will enhance the cybersecurity of hospitals and healthcare providers, helping them detect, monitor, and respond to cyber threats, particularly ransomware. This will boost the resilience of the European healthcare system, especially in the current geopolitical context, aligning with the EU action plan on cybersecurity in hospitals and healthcare.

full news

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

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.

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.

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ERN GENTURIS

With every diagnosis **we can help an entire family**

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