ERN GENTURIS Newsletter

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

July & August 2025

ERN GENTURIS news

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	4
TG4: Other rare – predominantly malignant – genturis	8

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 25 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

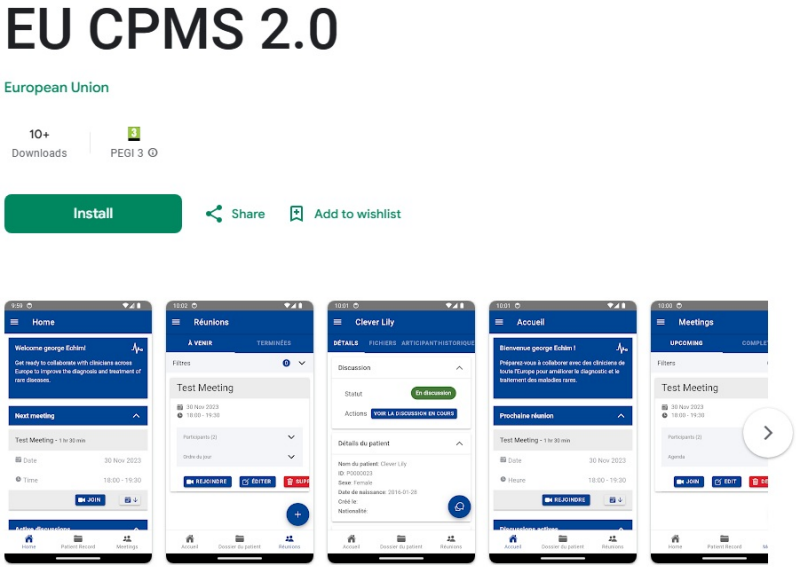
CPMS recurring meeting connectivity

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 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.

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

ERN Board of Member States meeting

During the meeting on 10 June 2025, the co-chair of the ERN Board of Member States (BoMS) was elected in two rounds of voting. Based on the result, Prof. Birute Tumiene was elected as co-Chair of the ERN Board of Member States for a second term.

The other key outcomes included approval of a new call for Affiliated Partners and progress on proposals to expand disease coverage, expected at the October plenary.

more information

ERDERA 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

EU budget proposal for the years 2028-2034

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

European Commission

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). This consolidation aims to streamline funding mechanisms and enhance Europe's global competitiveness.

The ECF is designed to support strategic sectors, including health, biotechnology, agriculture, and bioeconomy. Health initiatives within this framework are intended to align with the EU's broader objectives of innovation and economic resilience. However, this integration has raised concerns among stakeholders who fear that health may become secondary to economic priorities.

full news

EU4Health 2025 adopted

The EU4Health 2025 Work Programme has been adopted on 23 July 2025.

The call for proposals for a programme on **orphan medical devices** in particular targeting paediatric patients (HS-g-25-24) will be published in Q3-Q4/2025, see Annex to the EU4Health WP 2025 (p. 72) and the indicative budget is EUR 1 200 000.

Additionally, on 7 July, the Commission adopted Decision (EU) 2025/1324 to set up an expert panel on paediatrics and rare diseases, amending its Implementing Decision (EU) 2019/1396.

more information

New Orphadata & ORPHAcode Websites Launched

Orphanet has launched a new platform, Orphadata, to improve access to its

rare disease data and tools.

The new structure makes it easier to find:

- **Scientific datasets and ontologies** via *Orphadata Science*
- **Coding tools and implementation resources** via *ORPHAcode.org*
- **Expert services and APIs** via *Orphadata Products*

orphadata

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**

Share4Rare 2025 Call for Research Projects

Share4Rare has extended the deadline for its 2025 **research call** to **31 August 2025**. This initiative supports studies that gather patient-reported data on specific rare diseases or across disease groups.

Eligible project types include:

- Patient registries or observatories
- Natural history and burden of disease studies
- Quality of life research for patients and caregivers
- Scale creation or validation
- Correlation studies between patient-reported and clinical data

The selection process is **non-competitive**: all eligible proposals submitted by the deadline will be evaluated. Final service definitions and budgets will be agreed jointly with the Share4Rare team.

more information

FMR CALL FOR PROPOSALS 2025 identifying new therapeutic molecules for rare diseases

The French Foundation for Rare Diseases (FMR) is offering up to €40,000 per project for initiatives aiming to identify new therapeutic molecules for rare diseases. Eligible proposals may focus on high-throughput screening, in vitro mechanistic screening, or Hit-to-Lead optimisation. This program is open to research projects focused on all rare diseases.

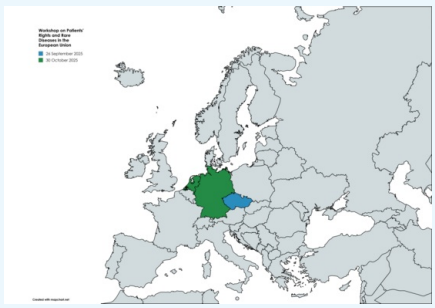
For rare cancers, the French National Cancer Institute (INCa) and the FFRD have jointly established the following criteria:
• Projects focused on primary malignant tumors should be submitted to INCa,
• Projects addressing benign tumors or systemic rare diseases with tumor development will be considered within this call.

Deadline: 4 September 2025, 17:00 CET

more information

Upcoming Meetings & Events

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.

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