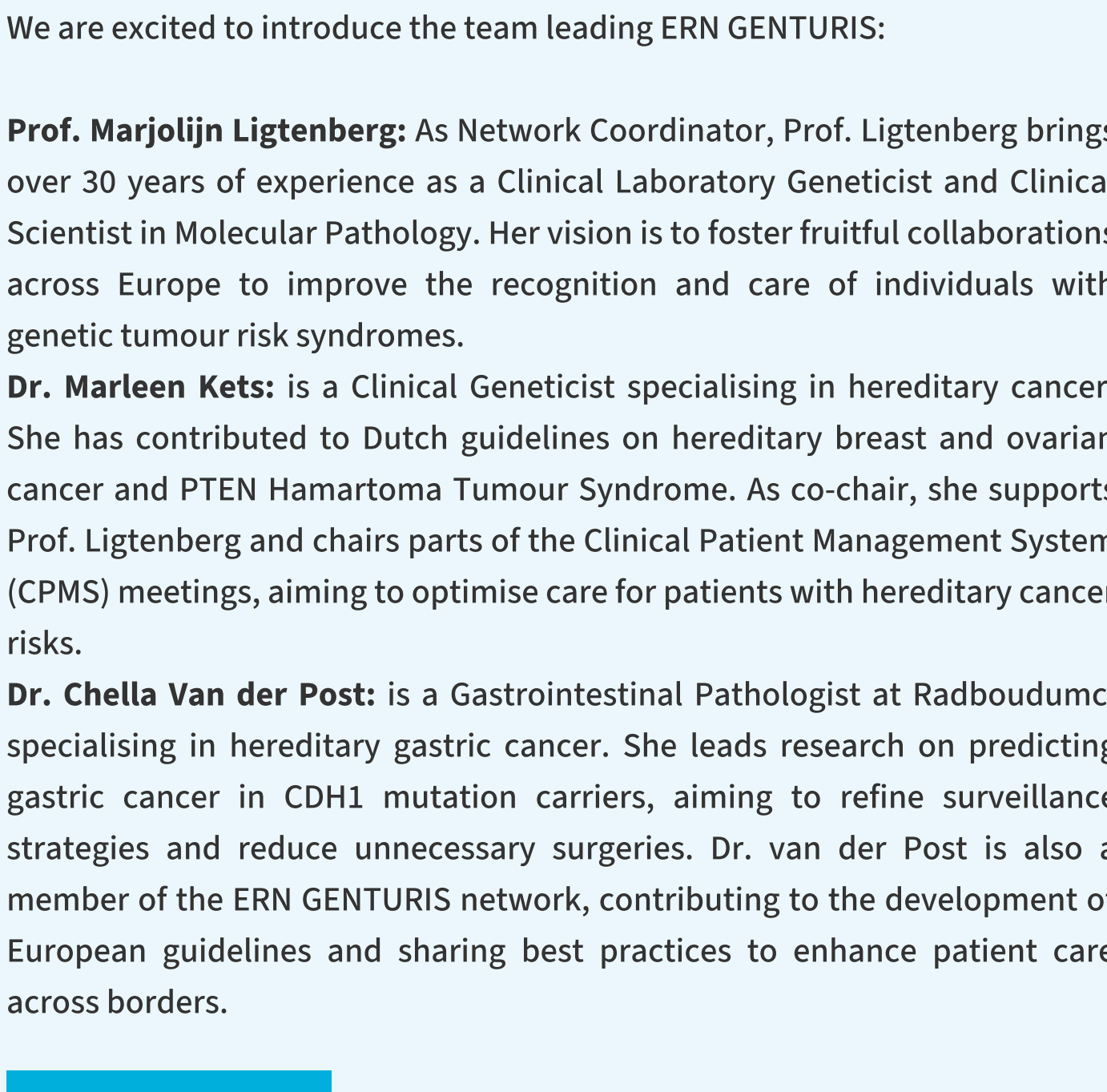


April 2025

ERN GENTURIS news

ERN GENTURIS Leadership Team

**Marjolijn Ligtenberg**
ERN GENTURIS Coordinator**Marleen Kets**
Clinical geneticist**Chella van der Post**
Pathologist

We are excited to introduce the team leading ERN GENTURIS:

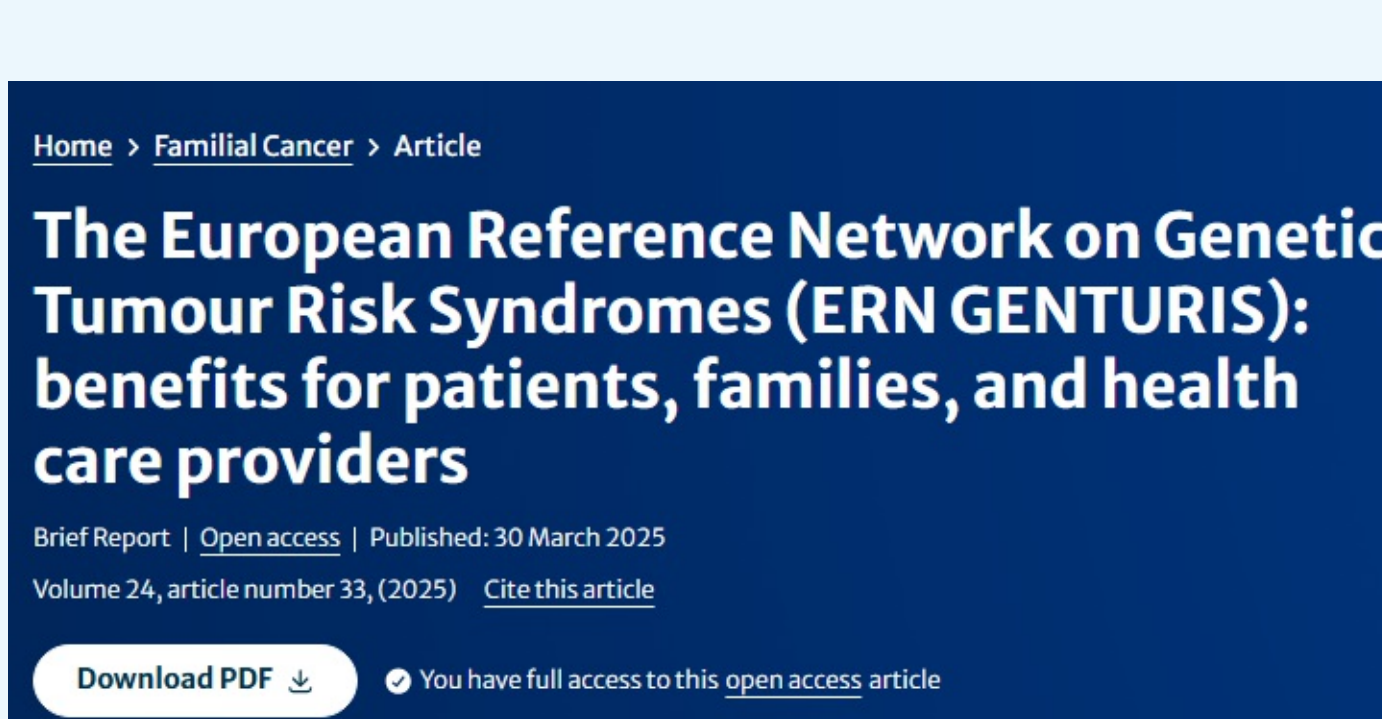
Prof. Marjolijn Ligtenberg: As Network Coordinator, Prof. Ligtenberg brings over 30 years of experience as a Clinical Laboratory Geneticist and Clinical Scientist in Molecular Pathology. Her vision is to foster fruitful collaborations across Europe to improve the recognition and care of individuals with genetic tumour risk syndromes.

Dr. Marleen Kets: is a Clinical Geneticist specialising in hereditary cancer. She has contributed to Dutch guidelines on hereditary breast and ovarian cancer and PTEN Hamartoma Tumour Syndrome. As co-chair, she supports Prof. Ligtenberg and chairs parts of the Clinical Patient Management System (CPMS) meetings, aiming to optimise care for patients with hereditary cancer risks.

Dr. Chella Van der Post: is a Gastrointestinal Pathologist at Radboudumc, specialising in hereditary gastric cancer. She leads research on predicting gastric cancer in CDH1 mutation carriers, aiming to refine surveillance strategies and reduce unnecessary surgeries. Dr. van der Post is also a member of the ERN GENTURIS network, contributing to the development of European guidelines and sharing best practices to enhance patient care across borders.

[in the spotlights](#)

Symposium of retiring ERN GENTURIS coordinator Nicoline Hoogerbrugge

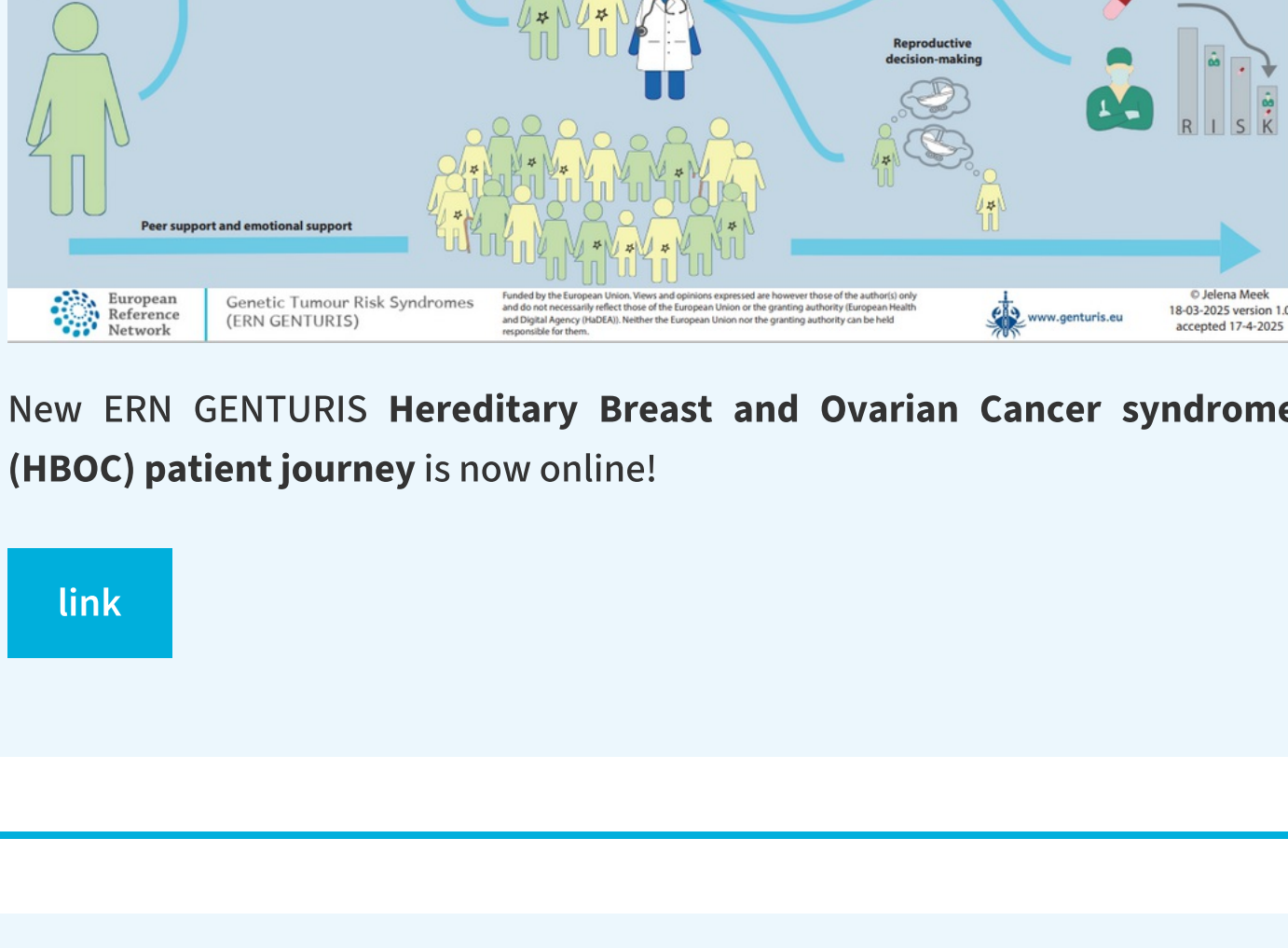


On 29 March 2025, Radboud University hosted a heartfelt symposium to mark the retirement of **Professor Nicoline Hoogerbrugge**, long-time coordinator of ERN GENTURIS. The event celebrated her impactful leadership and dedication to advancing care for patients with genetic tumour risk syndromes.

During the symposium, held in Dutch, Prof. Hoogerbrugge highlighted the importance of European collaboration through ERN GENTURIS, emphasizing how shared knowledge and cross-border cooperation have significantly improved patient outcomes. She also reflected on the network's achievements, including the development of clinical guidelines, increased awareness, and better access to expert care across Europe.

Her vision and commitment have left a lasting legacy within the rare disease community, and the symposium served as a fitting tribute to her exceptional contributions.

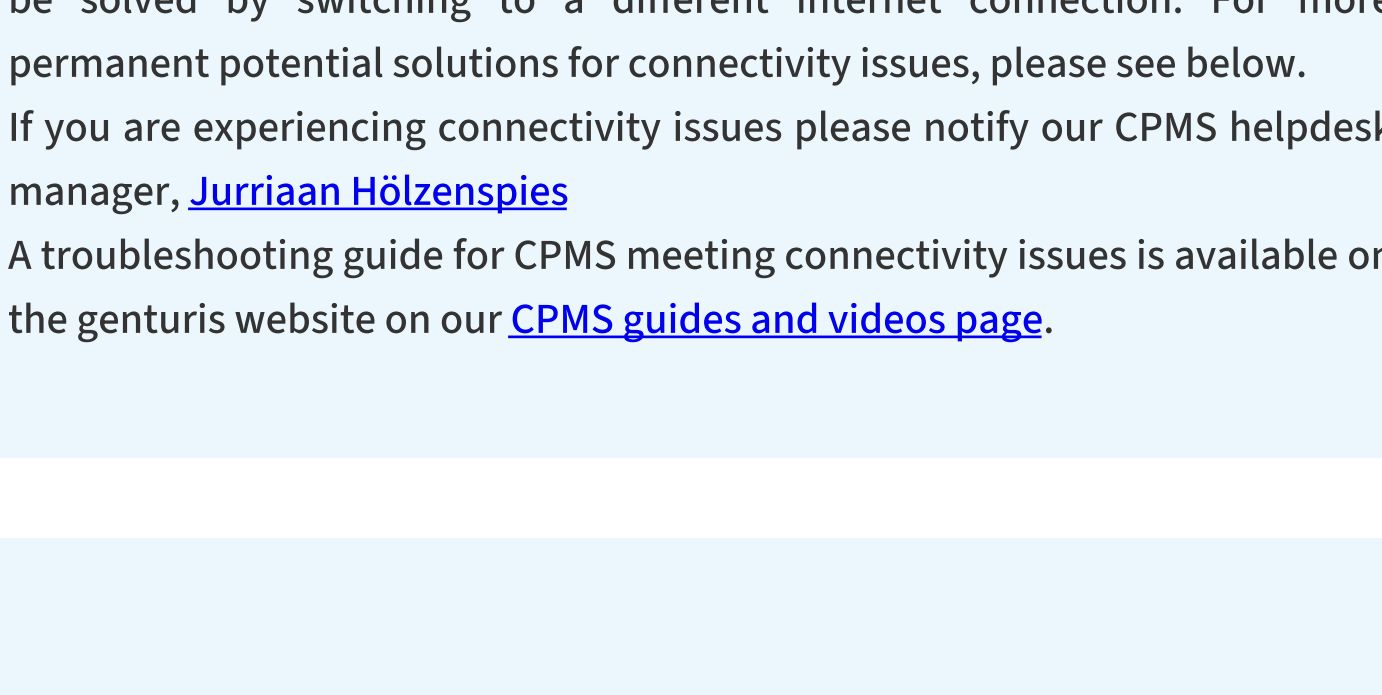
ERN GENTURIS Publications



The open-access publication **“The European Reference Network on Genetic Tumour Risk Syndromes (ERN GENTURIS): benefits for patients, families, and health care providers”** by Manon Engels et al. is a follow-up article of the publication in Familial cancer in 2019: boosting care and knowledge about hereditary cancer: European Reference Network on Genetic Tumour Risk Syndromes ([link](#)), and provides an overview of how ERN GENTURIS can benefit patients, families and healthcare providers.

[article](#)

ERN GENTURIS Patient Journey



New ERN GENTURIS **Hereditary Breast and Ovarian Cancer syndrome (HBOC) patient journey** is now online!

[link](#)

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	2
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 **11** 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](#).

Towards an EU action plan on rare diseases



ERN GENTURIS Project Manager, Katarzyna Urbanczyk, attended and supported the organisation of the two-day conference titled *“Towards an EU Action Plan on Rare Diseases”*, held on 10–11 April 2025 at the Medical University of Warsaw.

This important event—organised by the Polish Presidency of the Council of the European Union, the European Economic and Social Committee, the Polish Ministry of Health, and the Medical University of Warsaw—highlighted the urgent need for a comprehensive European policy framework aimed at improving the lives of patients with rare diseases and setting clear, measurable objectives.

The conference brought together policymakers, researchers, clinicians, and patient representatives from across Europe to discuss critical steps toward advancing rare disease care and fostering EU-wide collaboration.

To this end, it is crucial to continue driving forward the EU's political commitment in this area and to provide a platform where stakeholders can work together, share knowledge, and make meaningful progress toward a unified European response to rare diseases.

[article](#)

Education opportunities

ERN GENTURIS educational webinars

23 June 2025[Mosaicism in oncogenetics](#)

Janneke Schuurs-Hoeijmakers

Watch the previous webinars here:

[webinars](#)

General news

Commission public consultation on EU’s next long-term budget (MFF) – implementing EU funding with Member States and regions



The European Commission is preparing for the next multiannual financial framework (MFF), the EU's long-term budget, which will start in 2028. Following President von der Leyen's Political Guidelines for the 2024-2029 European Commission, the Commission aims to create a simpler, more focused, and responsive budget that reflects European strategic priorities. To achieve this, seven public consultations are launched to gather views from interested parties on how to make the most of the EU budget. The consultations will cover various policy areas, including cohesion policy, agriculture, and home affairs, with the goal of creating a more effective and efficient budget that delivers on key objectives. The Commission's proposals are expected to be presented in 2025.

Consultation period: 12 February 2025 - 06 May 2025 (midnight Brussels time).

[questionnaire](#)

Funding opportunities

European Commission Calls

- [HaDEA Calls for Proposals on Health](#)
- [HaDEA Calls for Tenders on Health](#)
- [Horizon Europe calls for Funding on Health](#)

Upcoming Meetings & Events

European Human Genetics Conference

ESHG 2025



The European Human Genetics Conference will take place on **24-27 May 2025** in Milan, Italy.

[more information](#)

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