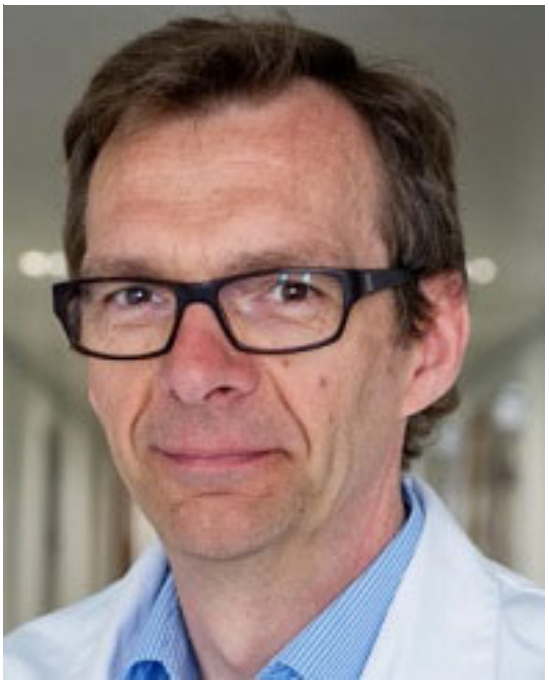
European Reference Network | Genetic Tumour Risk Syndromes (ERN GENTURIS)

Newsletter August 2023

ERN GENTURIS news



Thank you for your contribution to ERN GENTURIS!

ERN GENTURIS first representative of University Hospital Leuven **prof. dr. Eric Legius** will retire on the 1st of October 2023. The ERN GENTURIS network is grateful for his dedication and continuous improvement of patients' life. His contribution to a number of **ERN GENTURIS clinical practice guidelines**, numerous **webinars** and **the leadership of Thematic disease Group 1 – Neurofibromatosis** is only a glimpse of the things he did for the genturis patients and for the development of ERN GENTURIS as a Network!

We are extremely grateful to him!

We would like to welcome the new ERN GENTURIS first representative of University Hospital Leuven – **Prof. Hilde Brems,** who is a researcher at the Human Genetics Department of the University of Leuven, she was trained by Prof. Eric Legius. In 2007 they identified a new condition resembling neurofibromatosis type 1, now known as **Legius syndrome** (autosomal dominant condition caused by a heterozygous mutation in SPRED1). She is responsible for the molecular diagnostics of familial cancer syndromes with a main interest for neurofibromatoses, schwannomatosis and mosaic genodermatoses.

Education opportunities

Workshop on CDH1 Related Hereditary Diffuse Type Gastric Cancer

The registration for the upcoming ERN workshop, organized by ERN GENTURIS member Tanya Bisseling (Radboudumc) **"CDH1 Related Hereditary Diffuse Type Gastric Cancer: the shift from prophylactic total gastrectomy to optimal endoscopic surveillance" is still open.**
Register until August 31st 2023: here

The ESMO Preceptorship on Hereditary Cancer Genetics 2023

will be held on **29-30 September 2023 in Paris, France**. The course is co-chaired by **ERN GENTURIS members Judith Balmaña and Nicoline Hoogerbrugge**. This **accredited educational course** is primarily aimed at oncologists resident in Europe.

For more information check the link

Diagnosing Rare Diseases: from the Clinic to Research and Back

Would you like to discover the role of **research, clinical investigation and data sharing** in diagnosing rare diseases? Join the online course: **Diagnosing Rare Diseases: from the Clinic to Research and Back.**
In the context of the European Joint Programme for Rare Diseases EJPRD, **co-developed by Chrystelle Colas (ERN GENTURIS) and Laurence Faivre (ERN ITHACA), the Foundation For Rare Diseases, and EURORDIS**, this **Massive Open Online Course (MOOC)** addresses the diagnostic research progress, types of genetic tests for rare diseases, and the impact of having or lacking a diagnosis on patients' lives.
The MOOC is continuously open for enrollment and the access to the content is free for the first 5 weeks.

For more information check the link

Upcoming ERN GENTURIS educational webinars

06-09-2023
Lynch syndrome update
Prof. Elke Holinski-Feder

11-10-2023
Haematological malignancies – a genetic counselling perspective
Bev Speight

For more information visit www.genturis.eu

General ERN news

Study on Europe's Beating Cancer Plan

The European Commission (DG SANTE) and the European Health and Digital Executive Agency (HADEA) is conducting a study mapping and evaluating the implementation of **Europe's Beating Cancer Plan**. The aim of the study is to assess the state of play of the Europe's Beating Cancer Plan, identify further actions to support, coordinate and complement Member States' efforts against cancer, and build a monitoring framework to assess the outcomes of the Europe's Beating Cancer Plan. You can **share your views** on this before **8 September 2023** through this **link** for **civil society organisations** and this **link** for **healthcare professionals**.

ERICA 3rd General Assembly: Presentations

The **European Rare Disease Research Coordination and Support Action** (ERICA) held its 3rd General Assembly from 6-7 July 2023 in Madrid, Spain. These were two productive days full of interactive sessions. All the **presentations are now available from the ERICA website**.

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

Conference on Challenges in Cancer Care, 31 August

The Spanish Presidency of the EU Council, the Ministry of Health will hold a High-Level Conference about **"Challenges in Cancer Care".** The Conference will take place in **Barcelona on August 31.** The main objective of the conference is to reflect and discuss the current challenges and opportunities about comprehensive approach to cancer.

The event will be **streamed online** for those who did not register.

Conference on Rare Diseases and the ERNs, 10-11 October

The Spanish Presidency of the EU Council is organising a **conference on rare diseases and the ERNs** from **10-11 October 2023** in Bilbao, Spain. The conference will focus on strategies for overcoming the main challenges facing the EU policy framework on rare diseases and ERNs.
Registration for the conference is open now until 22 September 2023. However, places are limited, so **early registration is recommended**.

European Cancer Summit, 15-16 November

The **European Cancer Summit 2023** will be held in Brussels, Belgium and online on **15-16 November 2023** with the theme "**Accelerating Momentum: A Manifesto to 2030**". Commissioner Stella Kyriakides has confirmed her in-person participation.

ERICA & EJP RD Joint Conference, 21 November

The **ERICA & EJP RD Joint Conference** will be held in Amsterdam, the Netherlands on **21 November 2023** (with a pre-conference dinner on 20 November 2023).
The meeting will provide a closer overview of all the relevant activities and joint efforts in the field of **rare disease research** during the lifetime of **EJP RD** and **ERICA** with a further focus on the future **Rare Diseases Partnership** and **ERN research activities**.

ERN GENTURIS

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