

Newsletter December 2023

ERN GENTURIS news

Happy Holidays from the Coordination Team!



The ERN GENTURIS Coordination team wishes you all a **very happy and healthy** festive season!

We **thank you** for your contribution to ERN GENTURIS activities and congratulate you on all the achievements in 2023.

We are looking forward to the new year's opportunities and collaboration for the benefit of **patients, their families and caregivers**.

ERN GENTURIS publications

Check out the ERN GENTURIS recent publications:

- **MTHFR C677T and A1298C polymorphism's effect on risk of colorectal cancer in Lynch syndrome.** Published on 1 November 2023.
- **Gene-specific ACMG/AMP classification criteria for constitutional APC variants: recommendations from the ClinGen InSiGHT Hereditary Colorectal Cancer / Polyposis Variant Curation Expert Panel.** First published online on 3 October 2023.

Other publications are available [here](#)

Education opportunities

Upcoming 2024 ERN GENTURIS educational webinars

SAVE THE DATE

[14 February 2024](#)

**PTEN hamartoma tumor syndrome (PHTS, Cowden syndrome):
update on cancer risks and yield of surveillance**
Nicoline Hoogerbrugge

28 February 2024

Familial malignant melanoma - the dermatologist's perspective
Remco van Doorn

13 March 2024

Hereditary tumour syndromes for gastroenterologists
(pending registration link)
Verena Steinke-Lange

27 March 2024

TP53 variant classification
(pending registration link)
Thomas van Overeem Hansen

09 April 2024

Gastric Adenocarcinoma and Proximal Polyposis of the Stomach (GAPPS)
(pending registration link)
Lenka Foretova

24 April 2024

Variant interpretation and classification in cancer genes - Zipper model
(pending registration link)
Maria Haanpää

June 19 – 22, 2024
Barcelona



Submit your abstract by 15 January 2024

Abstract submission is still **open** for the **2024 Insight Biennial Conference** to be held in Barcelona at 19th-22nd June 2024. This conference focusses on the worldwide improvement of care of patients and families with any hereditary condition resulting in **gastrointestinal tumours**. All abstracts must be submitted online through the abstract submission system by **January 15th, 2024 by 23:59 CET**.

Conference directors are **Prof. dr. Nicoline Hoogerbrugge** (Radboudumc), **Dr. Gabriel Capellá** (CIO-IDIBELL Barcelona), **Dr. Francesc Balaguer** (Hospital Clinic, Barcelona) and **Prof. dr. Marjolijn Ligtenberg** (Radboudumc). For more information, see <https://tacticsmd.net/congreso/insight-2024>

FREE 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), Laurence Faivre (ERN ITHACA), and the Foundation For Rare Diseases**, the **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. You will be able to discover the role of **research, clinical investigation and data sharing** in diagnosing rare diseases.

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](#)

General news



Commission adopts EU4Health 2024 Work Programme

The 2024 EU4Health work programme was adopted to deliver on key EU health policy priorities as part of the European Health Union. The **€752.4 million budget** will boost its development and provide funding to address important health-related issues across the EU.

[Read more here](#)
Here is the full 2024 EU4Health work programme



European Commission and WHO/Europe sign €12 million agreement

WHO/Europe and the European Commission have embarked on an ambitious new partnership to strengthen health information systems and boost health data governance and interoperability in the WHO European Region. The €12 million project, funded by the European Commission, will support health-care services for the nearly 1 billion people living across the 53 countries in the Region.

[Read more here](#)



EP supports creating EU Health Data Space to boost access to data and research

On Wednesday 13 December 2023, MEPs adopted their position on creating a European Health Data Space to ease access to personal health data and boost secure sharing.

[Read more here](#)

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



On 15-16 May 2024, the **12th European Conference on Rare Diseases (ECRD)** will be held in Brussels and online! **Registration is open**, a limited number of 300 places are available to join in person, and early-bird fees are available until **2 February 2024**. Researchers, patient groups, healthcare professionals and any other interested parties in the rare disease community are invited to submit their **poster abstract** (maximum of 300 words, in English only). Poster abstract submissions for the ECRD 2024 are now open until **23rd February 2024**.

Learn more and submit your abstract now: [Posters - ECRD2024 \(rare-diseases.eu\)](#)
Find more info [here](#)



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With every diagnosis we can help an entire family

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