

Newsletter October 2023

ERN GENTURIS news



CDH1 Related Hereditary Diffuse Type Gastric Cancer

EJP RD - ERN two days workshop organized by ERN GENTURIS members: **Tanya Bisseling** and **Chella van der Post** took place in Nijmegen, the Netherlands on 12-13 October 2023.

19 participants and 11 speakers from different EU member states and Norway participated in this workshop. The experts were exploring the psychological, molecular, and administrative aspects of **CDH1-related hereditary diffuse type gastric cancer**. The workshop gave insights into the latest research findings and best practices in patient care.

Education opportunities

June 19 – 22, 2024
Barcelona



2024 InSiGHT Biennial Meeting

Abstract submission is now **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>

Upcoming ERN GENTURIS educational webinars

9-11-2023 16:00-17:00 CET

Monique van Leerdam

Lynch syndrome - the gastroenterologist's perspective

22-11-2023 16:00-17:00 CET

Carla Oliveira

CTNNA1 germline variants: genotype-phenotype associations

6-12-2023 16:00-17:00 CET

Eamonn Maher

Hereditary Leiomyomatosis and Renal Cell Cancer

For more information visit www.genturis.eu

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 ERN news

Open Letter: EU - Please stand by the ERNs



An open letter signed by all ERNs calling for a renewed and continuous **support** to the ERNs was published.

"We, the undersigned, representing the European Reference Networks (ERNs) and people living with a rare disease across Europe, call on the EU institutions and EU Member States' governments to stand by the European Reference Networks and to uphold their commitment to enable long-lasting impact in people's lives and,

fundamentally, give all people living with a rare or complex condition in Europe the same opportunities to access timely and adequate specialised healthcare."

[Read the whole letter](#)

Conference: Rare diseases and European Reference Networks



The Rare diseases and European Reference Networks conference: "**How to ensure European solidarity for patients?**" took place on 10 and 11 October in Bilbao, Spain. Among the attendees were top politicians, the Director General of DG SANTE Sandra Gallina, ERN representatives, patients, healthcare professionals, EURORDIS, Orphanet and many others. ERN GENTURIS was represented by Nicoline Hoogerbrugge, Katarzyna Urbanczyk and Ignacio Blanco.

On the day preceding the conference, ERN Coordinators and Project Managers held a closed meeting at the Hospital Universitario Cruces to discuss their core activities.

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

ERICA & EJP RD Joint Conference

21 November 2023

Amsterdam UMC
Meibergdreef 9, 1105 AZ Amsterdam Zuidoost
Noord-Holland



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**. **REGISTER BY 1 November**

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.



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With every diagnosis we can help an entire family

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