

Newsletter November 2023

ERN GENTURIS news

Annual ERN GENTURIS Meeting



On 2-3 November **ERN GENTURIS members** met in Amsterdam to discuss the importance of JARDIN, patient journeys, guidelines, registries, research, and the new CPMS amid other genturis topics.

Among invited speakers were: **Prof. Alberto Pereira**, ENDO-ERN and ERICA Coordinator, who explained the ERICA (European Rare Research Coordination and Support Action) project which aims to strengthen ERN's research and innovation capacity as well as the objectives of ENDO-ERN, **Sonja van Weely**, ZonMw, the Netherlands, who explained the JARDIN (Joint Action on Rare Diseases and ERN Integration into national healthcare systems) project, and **Dr Joao de Sousa**, European Commission representative, who shared the recent developments of CPMS 2.0 and a general overview of the EC policy with regard to ERNs.



The role of ERNs in precision health and precision medicine

Prof. Nicoline Hoogerbrugge, MD, PhD
Radboud university medical center, Nijmegen,
The Netherlands

2nd National Meeting of AIFET

The 2nd National Meeting of AIFET (Associazione Italiana Famigliarità ed Ereditarietà dei Tumori): **Precision Health meets Precision Medicine**, took place on 23-24 November 2023 in Rome. ERN Coordinator, **Prof. Nicoline Hoogerbrugge** explained "The role of European Reference Networks in precision health and precision medicine applied to cancer."

Course on Predisposition to Pediatric Malignant Diseases

On 22-24 November 2023, a course on **Predisposition to Pediatric Malignant Diseases** took place in Institut Curie,



Paris, France.

Dr Jurriaan Hölzenspies presented the establishment of clinical practice guidelines by ERN GENTURIS.

Education opportunities

Upcoming ERN GENTURIS educational webinars

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

Eamonn Maher

Hereditary Leiomyomatosis and Renal Cell Cancer

For more information visit www.genturis.eu

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>

FREE online course - Diagnosing Rare Diseases: from the Clinic to Research and Back

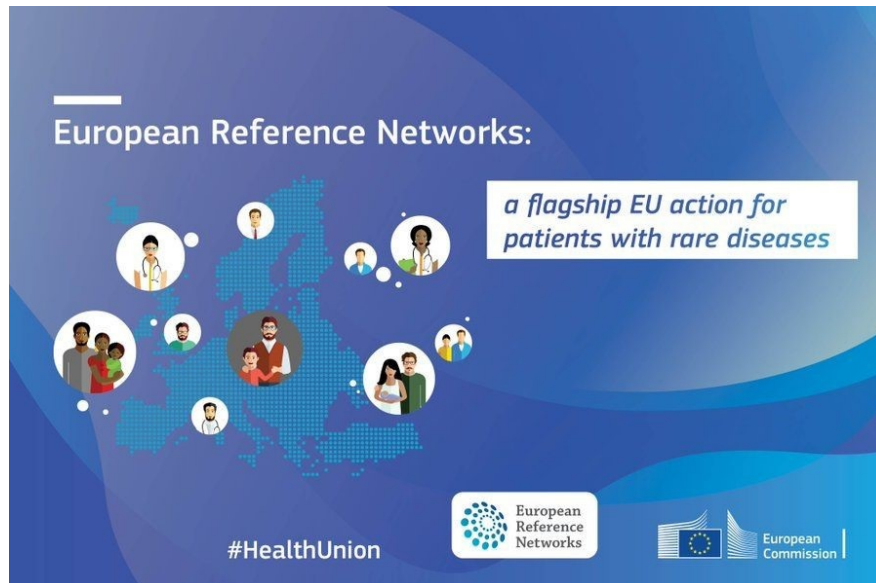
In the context of the European Joint Programme for Rare Diseases EJPRD, **co-developed by Chrystelle Colas (ERN GENTURIS), Laurence Faivre (ERN ITHACA), and the Foundation For Rare Diseases**, the **Massive Open Online Course (MOOC)** addresses the diagnostic research progress, types of genetic tests 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

European Reference Networks: A FLAGSHIP EU ACTION FOR PATIENTS WITH RARE DISEASES, says the EC



The **European Commission** recently published an article which stressed the importance of the ERNs.

Thanks to the **European Reference Networks** for Rare Diseases, the European Commission is making a difference to the lives of up to 36 million people across Europe who are living with a rare disease. This was the message of **Stella Kyriakides, European Commissioner for Health and Food Safety**, at the Spanish Presidency Conference on Rare Diseases in Bilbao on 11 October.

Read the full article: [here](#)

Check recently updated ERNs brochure: [here](#)



ERICA & EJP RD Joint Conference

The ERICA & EJP RD Joint Conference took place on 21 November 2023 in Amsterdam.

ERN GENTURIS was represented by **dr Nicoline Geverink**, on the picture with the ERN eUROGEN colleagues: **Prof Dr Wout Feitz, Loes van der Zanden** and **Lotte Boormans**.

Check out more info: [ERICA EJPRD](#)

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

Hebon Congress 2023

The **hereditary breast and ovarian cancer** congress will take place in the Jaarbeurs, Utrecht on Thursday the 30th of November at 09:00-18:00h CET. This congress will be held in Dutch.

All who are involved in research, counseling, screening, diagnosis, treatment or prevention of

hereditary breast and ovarian cancer are welcome to join!

[REGISTER HERE](#)



ESHG 2024

The next **European Human Genetics Conference** will take place on June 1 to 4, 2024 in Berlin, Germany. On Sunday, June 2, 2024 the session on ERNs: "**Get2gether European Reference Networks (ERN)**" will be held.

Check the **ESHG website 2024** and the programme: [here](#)



ERN GENTURIS

With every diagnosis we can help an entire family

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