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

Newsletter March 2024

ERN GENTURIS news

The National Coordinators Board leaders

The National Coordinators Board (NCB) advises the **ERN GENTURIS Board** on national issues and acts as platform to discuss national differences and find international solutions for GENTURIS, to “translate” centrally established output into national products and vice versa.

Dr. Ignacio Blanco - new chair

Works at Hospital Universitari Germans Trias i Pujol in Barcelona, Spain. Chairman at Clinical Genetics Department, Clinical Leader, at National Reference Center for Neurofibromatosis (CSUR Facomatosis) and Associate Professor at Department of Surgery, Universitat Autònoma de Barcelona.

Dr Blanco is an accomplished Clinical Geneticist with extensive experience in rare diseases and hereditary cancer and serving as a clinical leader in the management of neurofibromatosis. With a background in General and Digestive Surgery, coupled with specialized training in rare diseases. He is actively involved in various national and international genetic initiatives,

Dr. Tiina Kahre - new vice chair

Works at Tartu University Hospital in Tartu, Estonia. Head of the Department of Laboratory Genetics, Genetics and Personalized Medicine Clinic at Tartu University Hospital and Associate Professor at Department of Genetics and Personalized Medicine in Institute of Clinical Medicine, University of Tartu.

Dr Kahre is responsible for molecular diagnostics, metabolic, cytogenetics and newborn screening laboratories. She is also liable for the quality system in these laboratories, as well as for the introduction of new molecular genetic tests. For the last 10 years, Tiina Kahre's special interest has been the introduction of whole genome/exome sequencing in oncology

contributing significantly to scientific discourse through publications and conference presentations.

Dr. Ignacio Blanco is member of ERN GENTURIS since its approval in 2017 and he served as a Spanish National Coordinator and Thematic Group 1 leader.

and onco-haematology specially for patients with breast, ovarian, and colon cancer.

Dr. Tiina Kahre is a member of ERN GENTURIS since September 2019, when Estonia applied to be an Associated National Centre of ERN GENTURIS. She has served as a Estonian National Coordinator since 2022 and joined the Task Force 2 in 2023.

ERN GENTURIS acknowledgement

How to cite ERN GENTURIS in your publications?

If your publication has **co-authors from ERN GENTURIS member HCPs** from **two or more EU Member States**, one of the following acknowledgements can be used:

- "This work is generated within the European Reference Network on Genetic Tumour Risk Syndromes (ERN GENTURIS). ERN GENTURIS is funded by the European Union."
- "This work is supported by the European Reference Network on Genetic Tumour Risk Syndromes (ERN GENTURIS). ERN GENTURIS is funded by the European Union."
- "This work is supported (not financially) by the European Reference Network on Genetic Tumour Risk Syndromes (ERN GENTURIS)."

If the authors of the publication originate from **one EU Member State** only, or if the journal does not allow a phrasing like the one above, you can use:

- "[author names] are members of the European Reference Network on Genetic Tumour Risk Syndromes (ERN GENTURIS)."

A full list of ERN GENTURIS publications is available here.

Education opportunities

ERN GENTURIS educational webinars

09 April 2024
Gastric Adenocarcinoma and Proximal Polyposis of the Stomach (GAPPS) – not so infrequent disease
Lenka Foretova

24 April 2024
Variant interpretation and classification in cancer genes – Zipper model
Maria Haanpää

More on our website:
Webinars (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 news

Jardin Kick-off meeting

The Joint Action on Integration of ERNs into National Health Systems (JARDIN) kick-off meeting was held on 6 - 8 March 2024 in Brussels, Belgium. Two days of technical meetings were followed by a session organised by the European Economic and Social Committee on the last day: **'Rare Diseases in the EU: Joint Action shaping the future of ERNs'**, it highlighted a firm commitment among EU institutions, Member States and the rare disease community to progress towards connecting ERNs and national healthcare systems.
JARDIN is a three-years' project with the objective to integrate ERNs into national health systems and has total funding of €18.75 million (€15 million from the EU and €3.75 million from the Member States).

Commission designates first European reference laboratories for public health

The Commission adopted on 22 March 2024 the designation of the first **six European reference laboratories (EURLs)** for public health with the aim of further strengthening the EU's defences in the face of serious cross-border threats. The EURLs will bring together scientific expertise across the European Union, to improve preparedness, rapid detection and response.

Read more **here**

Commission welcomes political agreement on European Health Data Space

The Commission welcomes the political agreement reached ton 15 March 2024 between the European Parliament and the Council of the EU on the European Health Data Space (EHDS) - one of the **central building blocks of a strong European Health Union**.

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

Patient involvement in Guidelines

ERKNet/EURORDIS webinar on "Patient Involvement in Guidelines" by Matt Bolz-Johnson will focus on how patients can best contribute in the development phase and how clinicians can encourage patient involvement.
Date: Monday, April 22nd
Time: 17:30 - 18:15 CET

Register: here

EJP RD Final Conference

The EJP RD Final Conference, will be held in Bari, Italy from 27-28 May 2024 for invited people and will be open for all online .

The conference is set to bring together leading experts, professionals, and enthusiasts from around the world. Find more about the event **here.**

Registration deadline: 31 March 2024 - **here**

Pre-ESHG ERN GENTURIS meeting in Berlin, Germany

The next ERN GENTURIS meeting will take place prior to the ESHG conference in Berlin on 31 May and 1 June 2024. ERN GENTURIS members who attend the ESHG conference are invited to participate.

DATE: 31 May -1 June 2024

5th course in Hereditary Cancer Genetics, Bertinoro, Italy

This course, organised by members of the ERN GENTURIS, aims to deliver up-to-date knowledge on hereditary cancers to clinical and molecular geneticists in training or certified. The programme is available here and the registration will open soon. More information will follow.

SAVE THE DATE: 17-20 September 2024

ERN GENTURIS

With every diagnosis **we can help an entire family**

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