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ERN GENTURIS Newsletter

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

May 2024

ERN GENTURIS news

ERN GENTURIS Spotlights

Professor **Frederik Hes** is a clinical geneticist and a head of the department of Medical Genetics in UZ Brussel, Belgium. He joined ERN GENTURIS in January 2022.
In this interview he shares his academic and professional background, as well as the reasons why he got involved in ERN GENTURIS and why it is important to involve patients and patient representatives in ERN GENTURIS activities.

read the interview

Neurofibromatosis awareness day

On 16th May 2024, the Neurofibromatosis awareness day 2024 took place in the Institute of Oncology, Ljubljana, Slovenia. ERN GENTURIS Patient Representative - **Claas Roehl** - presented the role of patient organizations in improving care for NF1 patients and ERN GENTURIS Thematic Group 1 leader - **Dr Rianne Oostenbrink** gave a speech about the ERN GENTURIS NF1 guidelines and organisation of care in the Netherlands.

ERN Coordinators Meeting in Luxembourg

The ERN Coordinators meeting with DG SANTE and HADEA took place on 21 May 2024 in Luxembourg.

The ERN GENTURIS Coordinator **Nicoline Hoogerbrugge** and Project Manager **Nicoline Geverink** were there to discuss important points about the future of the ERNs.

ERN GENTURIS meeting in Berlin

The **ERN GENTURIS closed meeting** is taking place prior to the ESHG conference in Berlin on 31 May and 1 June 2024.
Around 50 ERN GENTURIS members registered to participate in this meeting. Among the discussed topics are: ERN GENTURIS guidelines, research, registries, patient journeys, and the new CPMS.

ERN GENTURIS overview of patients discussed in the CPMS in 2024

Thematic group	Number of patients discussed in ERN GENTURIS CPMS meetings in 2024
TG1: Schwannomatosis and neurofibromatosis	5
TG2: Lynch syndrome and polyposis	9
TG3: Hereditary breast and ovarian cancer	2
TG4: Other rare – predominantly malignant – genturis	11

In the discussions organized through the Clinical Patient Management System (CPMS), ERN GENTURIS has provided tailored expert advice to **27** genturis patients and their families in 2024 so far. For more information on how to refer a patient for discussion in an ERN GENTURIS CPMS meeting and how to use the CPMS, please see:

- How to refer a patient
- CPMS information and policy
- CPMS guides

Education opportunities

ERN GENTURIS educational webinars

24 June 2024
Familal malignant melanoma - the surgeon's perspective
Barbara Perić

More on our website:

webinars

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

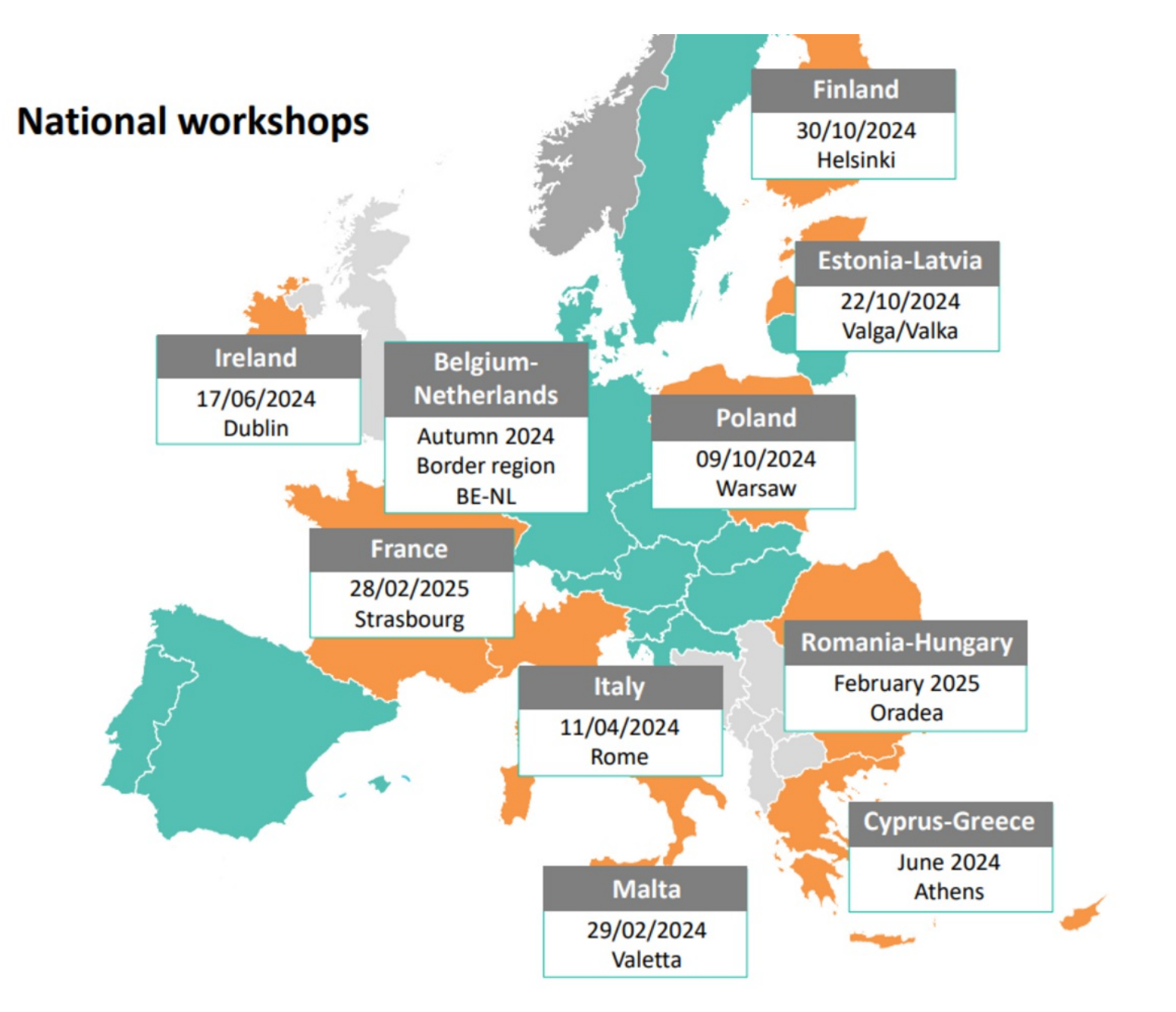
course

GENERAL NEWS

On Friday 3rd May, **Prof. Dr Wout Feitz**, Coordinator of ERN eUROGEN gave his farewell speech at the Radboud University.
ERN Coordinators of ERN GENTURIS - Nicoline Hoogerbrugge, Endo-ERN - Alberto Pereira and ERNICA - Rene Wijnen joined this historic moment.

ERN GENTURIS team would like to thank Wout Feitz for his work, dedication and continuous support to the ERNs community and helping to improve the life of patients!

A big THANK YOU!! eUROPAPA



In the context of enhancing the implementation of **Directive 2011/24/EU on patients' rights in cross-border healthcare (CBHC)**, under the EU4Health programme, the European Commission with assistance of the National Contact Points, is customising and improving written communication materials and organising a series of **10 workshops at national level, culminating in an EU-level event in 2025**. The next workshop will be held in Dublin, on 17 June, and you have the option to attend it online. The workshop will be in English.

Please register through the following link.

register

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

European Human Genetics Conference

On Sunday, 2nd June at 12:15 - 13:15 CEST the Get2gether European Reference Networks session will take place in Room A1.

Stop by the ERN booth (1-3 June) shared by ERN GENTURIS, ERN ITHACA, ERN-EYE and EURO-NMD, you will find us in the hall 4.2, with the posters.

more information

Pre-InSiGHT meeting for patients and patient representatives with Lynch syndrome or polyposis

On Tuesday, June 18, 2024 at 19:00 - 21:00 CEST, the online meeting for patients and patient representatives with Lynch syndrome or polyposis will precede the scientific conference of **the International Society for Gastrointestinal Hereditary Tumours** (InSiGHT) in Barcelona. It is organised in close collaboration with ERN GENTURIS.

The programme can be found here. Free registration is available at the following link:

register

5th course in Hereditary Cancer Genetics

This course, organized by members of **ERN GENTURIS**, aims at delivering up-to-date knowledge on hereditary cancers to clinical and molecular geneticists in training or certified. It creates the best opportunity for interaction and discussion with experts from all over Europe, in the fabulous environment of Bertinoro, the headquarters of the ESHG sponsored courses. The faculty combines experts from many fields of cancer genetics known for their didactic skills. Participants are encouraged to present a clinical or genetic case in a Poster format for on-site discussion.
The course will take place on 17-20 September 2024.

View the course flyer

more information

ERICA GA & ERN Research Conference

The European Rare Disease Research Coordination and Support Action consortium (ERICA) 4th General Assembly & ERN Research Conference will take place **11-13 December, 2024** in Udine, Italy.

This event is hosted by MetaBERN.

There will also be a Call on Abstracts related to ERN Research.

more information

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Website and LinkedIn

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