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

Newsletter January 2024

ERN GENTURIS news

ERN GENTURIS
With every diagnosis we can help an entire family

4 YEARS GRANT SIGNED

European Reference Network

The 4 years Grant Agreement was signed on 20 December 2023, it provides funding support for the enlargement, sustainability, and continuation of the coordination, management, and non-clinical activities of the ERN GENTURIS for 4 years from 1 October 2023 until 30 September 2027.

NF1 pocket guide

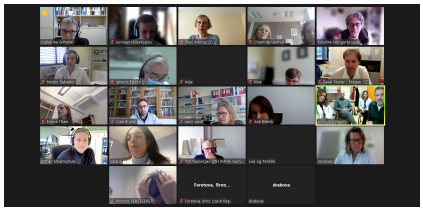
Surveillance protocol for tumour screening / identification in individuals with neurofibromatosis type 1

It is now available in several EU languages. Check out our webiste.

The pocket guide is the guideline summary presented on a pocket card.

ERN GENTURIS CPMS meetings

In ERN GENTURIS, we aim to involve experts from all of our member institutes in the multidisciplinary discussions (pictured) organized through the **Clinical Patient Management System (CPMS)**. One of our main goals is to **help as many genturis patients** as possibl.



All ERN GENTURIS member healthcare providing centres agreed to submit **at least two patient cases per year** to our CPMS, so we would like to take this opportunity to encourage you to join the CPMS and submit your genturis patient

cases.

To refer a patient to ERN GENTURIS from a **non-member hospital in the EU or EEA member states**, please see **Referring a patient** on our website.

The ERN GENTURIS CPMS meetings are held on the first and third Friday of every month and are split into two sessions:
12:30 – 13:30 Thematic group 1 (Neurofibromatosis)
13:30 – 14:30 Thematic groups 2-4 (Hereditary breast and ovarian cancer, Lynch/polyposis and other rare genturis)

If you have any questions or if you would like to submit cases and join our multidisciplinary discussions, please follow the steps outlined on our website or contact our CPMS helpdesk manager.

Education opportunities

ERN GENTURIS educational webinars

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

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

Belgian Presidency sets health priorities

The Belgian term takes place from the 1st of January to the 30th of June 2024.
The Belgian presidency programme sets out the priorities and main directions of the Belgian presidency of the Council of the EU.

ERICA & EJP RD Joint Conference in Amsterdam

The presentations and the recordings from the European Joint Programme on Rare Diseases (EJP RD) & the European Rare Disease Research Coordination and Support Action (ERICA) Joint

44 new EU4Health direct grants managed by HaDEA in the field of digital

Read more: here

Conference are now available.

health

HaDEA is now managing **44 new EU4Health direct grants** to EU countries and other countries associated to the EU4Health Programme. They are part of a wider portfolio of projects to support digitalisation in the health sector financed under the EU4H programme.

Read more: here

Funding opportunities

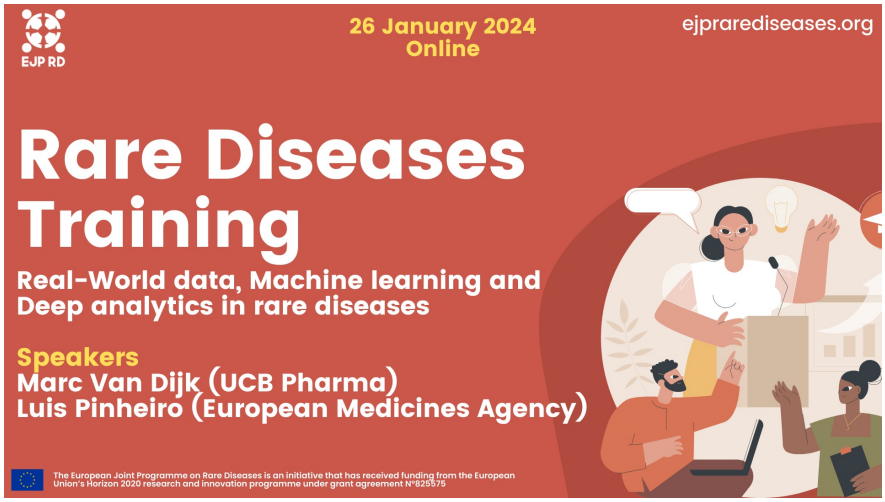
European Commission Calls

- HaDEA Calls for **Proposals on Health**
- HaDEA Calls for **Tenders on Health**
- Horizon Europe calls for **Funding on Health**

Upcoming Meetings & Events

ABTRACT SUBMISSION to 10th Biennial Meeting of the International Society for Gastrointestinal Hereditary Tumours extended until **21 January 2024.**

Check out the website: here



The European Joint Programme on Rare Diseases is organizing the training webinar: "Real-World data, Machine learning and Deep analytics in rare diseases: Regulatory grade data collection for marketing authorization submissions – what is buzz, what is realistic?" that will be held online on 26 January 2024 from 2:00pm to 4:00pm CET. More information here.

Registration is open here before 25 January 2024 at 23:45 p.m

12th European Conference on Rare Diseases (ECRD) will be held in Brussels and online on 15-16 May 2024, **the** ! **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

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. More information will follow.

SAVE THE 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**. More information will follow.

SAVE THE DATE: 17-20 September 2024

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Visit our: