

Newsletter



European
Reference
Network

Genetic Tumour Risk Syndromes
(ERN GENTURIS)

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Second Call for full membership of existing ERNs

The expected timeline for the Second Call for full membership of existing ERNs is as follows:

- publication ID (End of July 2019)
- call for new ERN members (Sep-Nov 2019)
- eligibility check by European Commission (Nov-Dec 2019)
- opinion of the ERNs (Dec 2019-Apr 2020)
- IAB assessment (May 2020-Oct 2020)

- approval procedure by the ERN BoMS (Nov-Dec 2020)

Affiliated Partner news

Malta has designated the Mater Dei Hospital (MDH) as a National Coordination Hub for ERNs. On the basis of this designation, MDH will be establishing a formal link with each of the 24 existing ERNs. ERN GENTURIS was already designated 5 Associated National Centres: 2 in Austria, 1 in Estonia, 1 in Latvia, and 1 in Norway.



Website cancergenetics.eu now available in Italian

The website www.cancergenetics.eu by ERN GENTURIS is now available in Italian as well! The website contains information for health professionals and patients who are considering a genetic test to look for an inherited cause of cancer. The website will be translated in other languages as well.



Nicoline Hoogerbrugge elected as vice-chair of the ERN Coordinators Group

Nicoline Hoogerbrugge, coordinator ERN GENTURIS, was elected new vice-chair of the ERN Coordinators Group during their meeting on 24 June in Brussels.

Irene Mathijssen (ERN CRANIO) took over from Franz Schaefer (ERN ERKNET) as Chairperson.

Next year, Nicoline Hoogerbrugge will become Chairperson.

ERN workshop in Gothenburg, Sweden,

17 June 2019

During the ESHG 2019 in Gothenburg, ERN GENTURIS members Conxi Lazaro (Barcelona) and Carla Oliveira (Porto) organized a workshop entitled: "European Reference Networks - What is in it for me?". This workshop intended to increase awareness about ERNs among of health professionals and scientists working in the field of Genetics in Europe. Besides Nicoline Hoogerbrugge and Elke Holinski-Feder from ERN GENTURIS, Birute Tumiene (BoMS Lithuania), Matt Bolz-Johnson (EURORDIS), Olaf Riess (Co-coordinator Solve-RD) and Alessandra Ferlini (ERN EURO-NMD) contributed to the workshop.



ERN GENTURIS meeting in Gothenburg, Sweden

14-15 June 2019

Prior to the ESHG (European Society of Human Genetics) meeting in Gothenburg, Members of ERN GENTURIS met to discuss genturis guidelines and communication strategies, and selection of indicators to monitor performance of the network.



ERNs newsletter

The first common newsletter to all ERNs has been published by DG Health and Food Safety. It features an article by Matt Bolz-Johnson about the ERN GENTURIS patient journeys.

Click [here](#) for the ERNs newsletter.

ERN registry call

The Consumers, Health, Agriculture and Food Executive Agency (CHAFAEA) has published the call for Rare disease registries for the European Reference Networks (ERNs). Read the call document [here](#)

Five ERNs have already received financial support from the Health Programme (Annual Work Plan 2016) and are currently developing their own rare disease registries. This call is now open for the remaining 19 ERNs to apply for financial support (200 000 EUR per ERN).

Task Force 5, lead by Janet Vos (Radboudumc) will take the lead in writing a proposal for ERN GENTURIS. The deadline for submission is 10 September 2019, with grants beginning in March 2020.

Two statements adopted on ERNs integration into the national health systems and cooperation with industry

The ERN Board of Member States adopted updated guidance principles to frame

collaboration between the ERNs and the industry, through a revision of its 2016 statement on the matter. It also adopted a new statement concerning recommendations and good practices to foster integration of the ERNs in national healthcare systems. For more information, see the [website of the European Commission](#).

ESMO Preceptorship course on hereditary cancer genetics in Lugano

A huge success for the ESMO Preceptorship Course on hereditary cancer genetics, organised by ERN GENTURIS for young oncologists and for general oncologists wishing to update their knowledge. Forty-two participants from 17 countries were the lucky ones selected from 150 applications (!). They attended lectures given by 7 ERN GENTURIS Members on 26-27 April 2019, in Lugano, Switzerland. [To view the lectures, click here](#).



Rare Disease Day 2019 conference in Maastricht, The Netherlands

At the Rare Disease Day 2019 conference in Maastricht, Nicoline Hoogerbrugge (coordinator ERN GENTURIS) and Matt Bolz-Johnson (EURORDIS) highlighted the importance of European Reference Networks (ERN) in cross border healthcare for rare diseases. The conference took place within the scope of INTERREG “EMRaDi” (Euregio Meuse-Rhine Rare Diseases) project, and was organized by VSOP (Dutch patient alliance for rare and genetic diseases).

See http://www.emradi.eu/nl/news/56_emr-zeldzameziektendag



Upcoming meetings:

- **ERN GENTURIS Annual Meeting 2019**, Amsterdam, 26-27 September 2019
- **ESHG-ERN Bertinoro course**, Bertinoro, Italy, 21-25 Sept 2020
- **EU NF conference**, Rotterdam, 10-13 Sept 2020 [<https://nf2020.nl/>]

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ERN GENTURIS Coordinating Center:
Radboud university medical center
The Netherlands

genturis@radboudumc.nl
<https://www.genturis.eu>

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