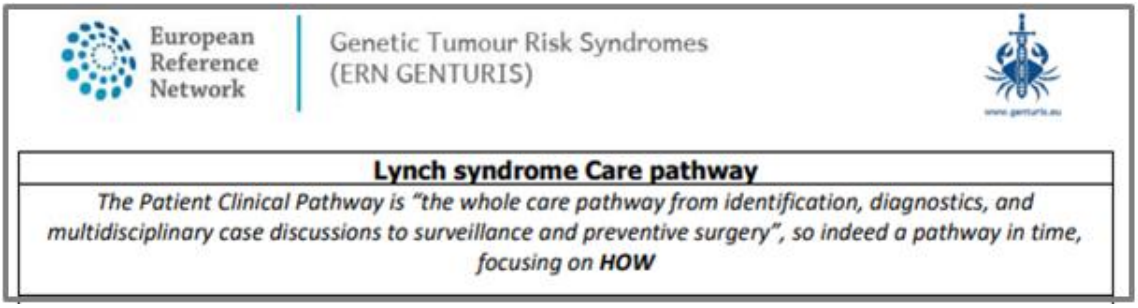
European Reference Network | Genetic Tumour Risk Syndromes (ERN GENTURIS)

Newsletter March/April 2023



The ERN GENTURIS Thematic Group on Lynch and Polyposis has updated the Lynch Syndrome Care Pathway. It is published on our website: https://www.genturis.eu/l=eng/Guidelines-and-pathways/Care-pathways.html

ESMO Preceptorship on Hereditary Cancer Genetics 2023

The ESMO Preceptorship on Hereditary Cancer Genetics 2023 will be held on 29-30 September 2023 in Paris, France.

The course is co-chaired by ERN GENTURIS members Judith Balmaña and Nicoline Hoogerbrugge, and among the speakers are ERN GENTURIS members Stefan Aretz, Marjolijn Ligtenberg, Carla Oliveira and Rolf Sijmons and Supporting Partners Gareth Evans and Marc Tischkowitz.

This accredited educational course is primarily aimed at oncologists resident in Europe, but application is open to all ESMO members.

Instructions for how to apply can be found here: https://www.esmo.org/meeting-calendar/esmo-preceptorship-on-hereditary-cancer-genetics-2023-paris. The application deadline is 27 June.

In the spotlight:
Meet Dr Remco van Doorn

ERN GENTURIS puts one of its new members in the spotlight:
Dr. Remco van Doorn, a dermatologist from Leiden, the Netherlands.
His special interest is in familial clustering of melanoma.
Read the interview here:
https://www.genturis.eu/l=eng/News-and-events/ERN-GENTURIS-Spotlights.html

Solve-RD Public Symposium, 26 April

The Public Symposium on The Impact of Solve-RD on Research & Care of Rare Disease Patients will be held online on Wednesday 26 April 2023 from 8:30-12:30 CEST. You can view the programme and register here. The Solve-RD project is a collaboration of four European Reference Networks: ERN-RND, EURO-NMD, ITHACA and ERN GENTURIS.

Webinar: Mainstreaming – method or madness?

Wednesday 26 April 2023, 16:00-17:00 CEST

In this webinar, Marc Tischkowitz (UK) and Judith Balmaña (Spain) will compare and contrast their experiences of implementing mainstream genetic testing for common hereditary cancer types.
Registration: https://attendee.gotowebinar.com/register/6950749001959022679

Marc Tischkowitz is a Professor of Medical Genetics and Honorary Consultant in the Department of Medical Genetics at Cambridge.

Much of his research has been on the Fanconi Anemia genes and hereditary breast cancer predisposition, but his interests cover all areas of hereditary cancer and translating the recent advances in genomic technology into clinical practice.

Judith Balmaña is the Head of the Hereditary Cancer Genetics Group at Vall d'Hebron Institute of Oncology (VHIO) and professor at the Faculty of Medicine in the International University of Catalonia, and the hereditary cancer track coordinator of the Master in Genetic Counseling (UAB). In 2005, she was involved in establishing the Familial Cancer Program in the Medical Oncology Department at Hospital Vall d'Hebron (HVH). Since then, she has been leading this program and serving as an Attending Physician in the Breast Cancer Unit.

Upcoming ERN GENTURIS webinars

10-05-2023
Rolf Sijmons
Liquid biopsy: the future of surveillance in individuals with inherited cancer predisposition?

07-6-2023
Gareth Evans
New ERN GENTURIS NF1 guidelines and update on NF2 and SCHWN nomenclature

For more information and registration, visit www.genturis.eu

General ERN news

It has been a very busy start of 2023 for the 24 European Reference Networks, with the five-year evaluation of the ERNs and their Full Members (recently submitted), the annual monitoring data collection (still running), and meetings with DG SANTE and HaDEA about the grants for the upcoming 4 years.

ERN and HCP evaluation

For the evaluation, the ERN GENTURIS coordination team and their ePAGs were interviewed on 7 March. The evaluators were very positive about the network's progress and activities. Four of our ERN GENTURIS HCPs will be visited for an on-site audit by the evaluators.

Call for ERN Grants 2023-2027

The EC has invited the 24 European Reference Networks to submit proposals for grants to support for the coordination, management, and operational activities of the ERNs from September 2023 – September 2027 under the EU4Health work programme. All ERN Coordination Teams are currently working hard to submit their applications by 25 May 2023.

Towards a simple and easy-to-use CPMS

A dedicated Business Implementation Group is regularly meeting to discuss the new CPMS being developed by IBM, expected to launch by the end of 2023 with a final version in Summer 2024. ERN GENTURIS is represented by CPMS manager Jurriaan Hölzenspies, and ERN GENTURIS members Jonas Arnold (Hereditary Cancer Syndrome Centre Dresden) and Robin de Putter (Ghent University Hospital) .

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