

# Newsletter



European  
Reference  
Network

Genetic Tumour Risk Syndromes  
(ERN GENTURIS)

October 2021 | [www.genturis.eu](http://www.genturis.eu)



## Webinar 'Update in therapeutic options for Lynch-associated colorectal cancer patients'

**Wednesday 13 October 2021, 16:00-  
17:00 CEST**

**Dr. Iosune Baraibar, Vall d'Hebron  
University Hospital, Barcelona**

Iosune Baraibar Argota, MD, PhD, works in the Gastrointestinal and Neuroendocrine Tumors Unit of the Vall d'Hebron University Hospital in Barcelona on the development of new molecular therapies based on immunotherapy and the study of the microbiome and colorectal cancer in young patients.

Dr Argota will focus in this webinar on therapeutic options for Lynch-associated colorectal cancer patients. Identification of individuals with inherited predispositions to cancer, including Lynch syndrome, allows for the uptake of specific screening and management that in the long term impacts in cancer prevention and cancer-related death.

If you would like to attend this webinar, please register here:  
<https://register.gotowebinar.com/register/3123864683398709516>

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## Webinar 'PTEN hamartoma tumour syndrome in childhood'

Thursday 21 October 2021, 16:00-17:00 CEST

Jolanda Schieving, MD, Radboudumc, Nijmegen



Jolanda Schieving is a paediatric neurologist at the Amalia children's hospital / Radboud university medical center in Nijmegen, The Netherlands.

PHTS is autosomal dominant condition starting in childhood. Most frequent problems in childhood are hypotonia, macrocephaly, developmental delays, autism spectrum disorder, learning difficulties, dental concerns, thyroid disorder with a highly variable phenotype. In this webinar the speaker will share her experience from the 115 children (0-18 years) in the Amalia children's hospital in Nijmegen.

If you would like to attend this webinar, please register here:  
<https://register.gotowebinar.com/register/8836755578275895566>

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## Gastrointestinal stromal tumours: ESMO–EURACAN–GENTURIS Clinical Practice Guidelines for diagnosis, treatment and follow-up

A Clinical Practice Guideline providing key recommendations on the management of gastrointestinal stromal tumours is now available online. The publication by Casali *et al.* lists the recommendations which have been agreed following a consensus meeting of representatives from ESMO, EURACAN and ERN GENTURIS. See <https://doi.org/10.1016/j.annonc.2021.09.005>

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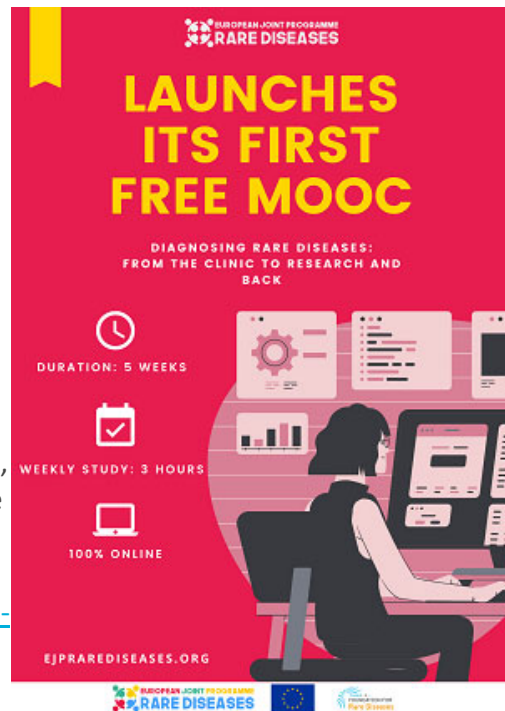
## Endorsed Guidelines

ERN GENTURIS recently endorsed existing guidelines on Lynch syndrome and polyposis, hereditary CRC and DICER1. For more information on these guidelines, see <https://www.genturis.eu/l=eng/Clinical-practice-guidelines.html>

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## Diagnosing Rare Diseases: From the Clinic to Research and back Second run from October 4th!

The second run of the MOOC (Massive Open Online Course) “Diagnosing Rare Diseases: From the Clinic to Research and back” co-developed by EJP-RD, ERN ITHACA, ERN GENTURIS and the Foundation for Rare Diseases will start on October 4th. Registrations are free and open here: <https://www.futurelearn.com/courses/rare-genetic-disease>.



1800 learners from 117 countries (40% outside Europe) joined the first session, which received a 91.5% positive feedback and learners contributed with 1836 comments.

We specifically encourage medical and biomedical science students to register and follow the MOOC.

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## Save the date: ERN GENTURIS 5-year anniversary conference on 10-11 Feb 2022

On 10-11 February 2022, ERN GENTURIS will celebrate its 5-year anniversary with a free online conference. The conference will feature updates on the ERN GENTURIS tumour predisposition syndromes, reports on special ERN GENTURIS projects and patient perspectives. It will also include a half-day introductory educational session specially aimed at general practitioners.

More details on the conference program and registration will be available soon via <https://www.genturis.eu/l=eng/News-and-events/ERN-GENTURIS-conference-Feb-2022.html>

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## Upcoming webinars:

Wednesday 10 November: Rianne Oostenbrink (Erasmus MC, Rotterdam) –

NF1 from the paediatric perspective

Wednesday 24 November: Stefan Aretz (University Hospital Bonn) –  
Somatic Mosaicism in Tumour Genetics

Tuesday 7 December: Eric Legius (KU Leuven) –  
Legius syndrome and its link with Neurofibromatosis type 1

For more information on webinars and registration, visit [www.genturis.eu](http://www.genturis.eu)

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## ERN GENTURIS

### Coordinating Center:

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The Netherlands

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