

Newsletter



European
Reference
Network

Genetic Tumour Risk Syndromes
(ERN GENTURIS)

March 2021 | www.genturis.eu

Continued rare cancers collaboration with European Reference Networks after Brexit

In a letter published on 26 February in the Lancet, the four ERNs dedicated to rare cancers (EURACAN, EuroBloodNet, ERN GENTURIS, and PaedCan) express the wish to actively continue collaboration with their much-valued UK colleagues. DOI: [https://doi.org/10.1016/S0140-6736\(21\)00264-6](https://doi.org/10.1016/S0140-6736(21)00264-6)

ERN recommendations on COVID-19 vaccination for patients with rare diseases

All ERN Coordinators have worked together to establish recommendations on the COVID vaccination program for rare disease patients. Prof. Nicoline Hoogerbrugge, as chair of the ERN coordinators group, presented these recommendations to the European Health Security Committee on 10 February. The European Commission will distribute the recommendations to all Member States. The recommendations can be found here:

https://www.genturis.eu/l=eng/Assets/20210205_summary_ERN_COVID-19_Vaccination_DEF-1905.pdf

ESMO Virtual Preceptorship on Hereditary Cancer Genetics 2021

The ESMO Virtual Preceptorship on Hereditary Cancer Genetics 2021 will be held online on 27 May and is now open for applications. The course is co-chaired by ERN GENTURIS members Judith Balmaña and Nicoline Hoogerbrugge, and the speakers are all ERN GENTURIS Full Member or Supporting Partner: Stefan Aretz, Gareth Evans, Marjolijn Ligtenberg, Rolf Sijmons and Marc Tischkowitz. This accredited educational course is primarily aimed at oncologists resident in Europe, but application is open to all ESMO members. There is room for 65 participants. Instructions for how to apply can be found here:

<https://www.esmo.org/meetings/esmo-virtual-preceptorship-on-hereditary-cancer-genetics-2021>



Rare Disease Day 2021

Rare Disease Day takes place on the last day of February each year to raise awareness about rare diseases and their impact on patients' lives. On rarediseaseday.org you can find information about the thousands of events which were happening around the world on 28 February this year.

Watch EJP RD contributors answer the web's most search questions about rare diseases in a new video that you can find [HERE](#) (subtitles available):

<https://www.youtube.com/watch?v=n0EOCX3ghIM&feature=youtu.be>



Webinar 'Von Hippel-Lindau disease: from clinic to gene and back'

17 March 2021, 16:00-17:00 CET

Professor Eamonn Maher, University of Cambridge, UK

Professor Eamonn Maher, Department of Medical Genetics, University of Cambridge is a clinician scientist who researches clinical and molecular aspects of hereditary cancer with a particular interest in hereditary kidney and endocrine tumours. This webinar will cover the clinical and molecular genetic basis of VHL disease and illustrate how rare diseases can provide a paradigm for elucidating the pathogenesis and informing the treatment of more common disorders.

If you would like to attend this webinar, please register here:

<https://attendee.gotowebinar.com/register/9003596567238499340>



Webinar 'Psychological aspects on the *TP53* related cancer syndromes'

31 March 2021, 16:00-17:00 CEST

Professor Yvonne Brandberg,
Karolinska Institutet, Stockholm

Professor Yvonne Brandberg, Department of Oncology-Pathology, Karolinska Institutet is a researcher within the psycho-oncological research area, and a clinical psychologist focusing on patients with hereditary cancer. This webinar will focus on psychological reactions of undergoing genetic consultations and testing for *TP53* related cancer syndromes. In addition, the decision making process will be discussed, as well as ethical aspects of testing of children. Psychosocial aspects of surveillance will also be discussed.

If you would like to attend this webinar, please register here:

<https://register.gotowebinar.com/register/8328564595799392269>

Upcoming webinars:

14 April: Revisiting penetrance in cancer genetics – Prof. Thierry Frebourg, Rouen

28 April: ERN GENTURIS: The EU highway for these rare diseases – Prof. Nicoline Hoogerbrugge, Nijmegen

For more information on these webinars or for registration, please visit www.genturis.eu.

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