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Newsletter

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

July 2020 | www.genturis.eu

Two new ERN GENTURIS guidelines available

The complete ERN GENTURIS Surveillance guidelines for:

- **Heritable TP53-related cancer Syndrome (hTP53rc)** (Li-Fraumeni syndrome)
- **PTEN hamartoma tumour syndrome (PHTS)** (Cowden syndrome)

as well as a pocket guide and the associated publications in the European Journal for Hereditary Genetics are now available!

See https://www.genturis.eu/l=eng/Clinical-practice-guidelines.html for more details.

SCCOHT Guideline endorsed by ERN GENTURIS

ERN GENTURIS endorsed a guideline on SSCOHT (Small-Cell Carcinoma of the Ovary, Hypercalcemic Type) by Tischkowitz et al (DOI: 10.1158/1078-0432.CCR-19-3797). ERN GENTURIS evaluated the SCCOHT guideline against international best practice, using the Appraisal of Guidelines for Research & Evaluation tool (AGREE 2), to assess the quality and independence of the guideline according to the ERN GENTURIS policy.

Development of guidelines for neurofibromatosis type 1 (NF1) and Schwannomatosis

Several of our ERN GENTURIS members are closely involved in the development of the new ERN GENTURIS guidelines for neurofibromatosis type 1 (NF1) and Schwannomatosis. The guideline development teams are a good representation of experts on these topics, both within and outside our ERN, and have discussed the main clinical questions to be answered. The NF1 guideline focusses on the different tumours caused by NF1, aiming to come up with advices that fit all European centres. The Schwannomatosis guideline will be the first standalone guideline on Schwannomatosis and aims to define the optimal diagnosis, clinical management and surveillance of people with Schwannomatosis. Both groups are currently working on the recommendations.

ERN GENTURIS Webinars

Recordings of the first three ERN GENTURIS webinars can still be viewed online: check our website.

And you can already register for the webinar on 30 September by Prof. Elke Holinski-Feder on “HNPCC related tumour risk syndromes like Lynch Syndrome, Lynch-like syndrome and familial colorectal cancer type X – pathomechanims and clinical implications” via this registration link.

3rd Course in Hereditary Cancer Genetics in Bertinoro postponed to 20-24 September 2021

The third edition of the ERN GENTURIS course Hereditary Cancer Genetics is postponed for a year due to the coronavirus. The course will take place on 20-24 September 2021 in Bertinoro, Italy. The course aims at delivering up-to-date knowledge on hereditary cancer to clinical and molecular geneticists in training or certified. It creates the best opportunity for interaction and discussion with experts from all over Europe. Updated information on registration forms and deadlines, fellowship applications, accommodation and venue, will become available at https://www.eshg.org/courses.0.html
and www.ceub.it.

European NF meeting 2020 in Rotterdam rescheduled to 10-13 December 2020

european
neurofibromatosis
meeting 2020
rotterdam

The 19th European neurofibromatosis meeting in Rotterdam, organised by ERN GENTURIS Member Erasmus MC and the patient organisation for neurofibromatosis in the Netherlands (NFVN) is rescheduled to 10-13 December. For more info, see https://nf2020.nl/

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