Radboudumc
university medical center

Newsletter

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

Edition 2 | November 2018 | www.genturis.eu

Annual ERN GENTURIS meeting in Amsterdam

27-28 September 2018

The annual ERN GENTURIS meeting took place near Schiphol Airport, The Netherlands, on 27 and 28 September 2018. The patient representatives presented the disease specific 'patient journeys' they developed, seen from the perspective of patients and parents. These patient journeys can function as a point of reference for pathways and guidelines.
A dedicated CPMS training was given by Jean-Marie Misztela, DG Sante Unit A4 – Information systems & Hany MINA, OpenApp. Daria Julkowska (Inserm) gave a

presentation about the European Joint Programme on Rare Diseases (EJP RD), in which ERN GENTURIS will participate. EJP RD is an EU-wide and patient-centred initiative to foster rare disease research from bench to bedside and back and is due to launch in January 2019.

ERN GENTURIS helpdesk CPMS available now!

Jelena Meek and Sander van den Groenendaal are our new Clinical Patient Management System (CMPS) Helpdesk employees. From this month onwards, they will help the ERN GENTURIS members to become familiar with all details of the CPMS and CP (Collaborative Platform).

ERN GENTURIS participates in the European Joint Programme on Rare Diseases (EJP-RD)

EJP-RD, recently approved by the European Commission, is an EU-wide and patient-centred initiative to foster rare disease research from bench to bedside and back. The programme, which is due to launch in January 2019, will receive 55 million EUR over 5 years to establish a comprehensive strategy covering research, data, tools and clinical aspects. The goal is to increase the efficiency of results use, diagnosis, drug discovery and patient care, and to empower all stakeholders.
Read more

Website cancergenetics.eu online

The website www.cancergenetics.eu was launched by ERN GENTURIS. The website contains information for health professionals and patients who are considering a genetic test to look for an inherited cause of cancer. Informative videos and referral tests are available in Dutch and English for now, but will be translated in other languages as well.

Open access publication about ERN GENTURIS

An open access peer reviewed publication about ERN GENTURIS is online now:
Janet R. Vos, Lisette Giepmans, Claas Röhl, Nicoline Geverink, Nicoline Hoogerbrugge, ERN GENTURIS (Full Members of the ERN GENTURIS are listed in the acknowledgements). Boosting care and knowledge about hereditary cancer: European Reference Network on Genetic Tumour Risk Syndromes.
Published in Familial Cancer on 9 October 2018.
(*https://doi.org/10.1007/s10689-018-0110-6*).

Funding for PHTS research

The UK PTEN Research Foundation is funding a research project of Janet Vos, Nicoline Hoogerbrugge and Marleen Kets (Radboudumc). The aim of their project is to refine cancer risk estimates for people with PTEN Hamartoma Tumor syndrome (PHTS). The study will examine data from families and individuals with PHTS from expert centers participating in, or collaborating

with, ERN GENTURIS. The team hopes this work will pave the way for improved cancer detection, prevention and risk-based recommendations for people living with PHTS. The project will start in January 2019 and it will run for two years.

Agenda

2-6 November
2018 Joint Global Neurofibromatosis Conference, Paris, France. (http://www.nf-paris2018.com)

20 November
6th ERN Coordinators Group Meeting, Brussels, Belgium.

21-22 November
Fourth ERN Conference "ERNs in action, Brussels, Belgium.

How to unsubscribe?

You received this newsletter because you are a contact of ERN GENTURIS. If you no longer wish to receive newsletters, please unsubscribe.

ERN GENTURIS Coordinating Center:
Radboud university medical center
The Netherlands

genturis@radboudumc.nl
http://www.genturis.eu

Unsuscribe