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Newsletter

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

April 2022 | www.genturis.eu


Ariane Weinman


Claas Röhl


Tamara Hussong Milagre

Webinar 'How EURORDIS and other patient organisations collaborate with the ERN GENTURIS'

Wednesday 20 April 2022, 16:00-17:00 CEST

Ariane Weinman, Public Affairs Senior Manager, EURORDIS-Rare Diseases Europe
Claas Röhl, Chairman of the Austrian patient organisation for NF patients "NF Kinder"
Tamara Hussong Milagre, President of Evita (Portuguese Association of carriers of genetic mutations related to Hereditary Cancer)

In collaboration with EURORDIS, the members of the GENTURIS ePAGs Council team up with the ERN GENTURIS members and bring the patients' perspective in the various activities undertaken by the network. This webinar will present the collaboration between the ERN GENTURIS and EURORDIS and the ePAGs Council, then Mr Claas Röhl will present the participation of patients' representatives in the development of clinical guidelines for specific diseases and Mrs Tamara Hussong-Milagre will present the development of Patient Journeys and how patient representatives promote the work carried out within the ERN GENTURIS.

For more information, click here:
https://www.genturis.eu/l=eng/Education-and-Training/Webinars/20-4-2022.html

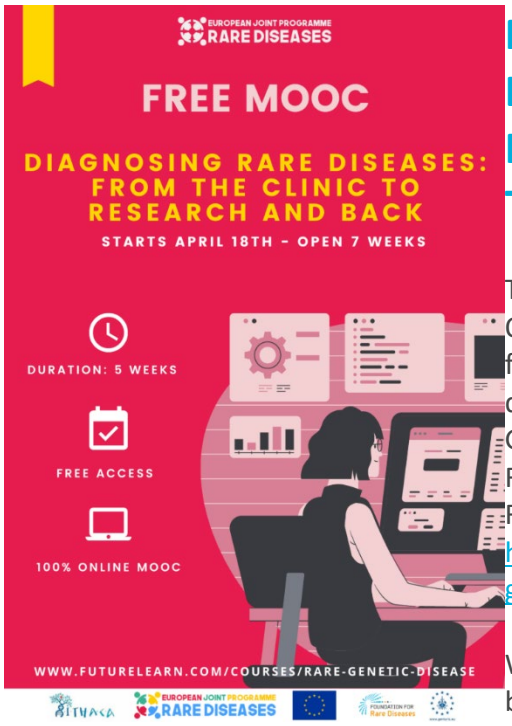
If you would like to attend this webinar, please register here:
https://register.gotowebinar.com/register/6102275662669871885

Schwannomatosis guideline published

The *ERN GENTURIS clinical practice guidelines for the diagnosis, treatment, management and surveillance of people with schwannomatosis* are now published in the European Journal of Human Genetics:
https://www.nature.com/articles/s41431-022-01086-x.
It is the first stand-alone guideline on schwannomatosis! We are very grateful to the ERN GENTURIS guideline group who put a lot of time and effort in developing this guideline.
The complete guideline and pocket guide can be found on our website as well:
https://www.genturis.eu/l=eng/Guidelines-and-pathways/Clinical-practice-guidelines/Schwannomatosis.html

Special ERN GENTURIS issue of the European Journal of Medical Genetics

Nine papers have already been published in the special ERN GENTURIS issue of the European Journal of Medical Genetics!
Go to https://www.sciencedirect.com/journal/european-journal-of-medical-genetics/special-issue/10PFC6MB478 to read them all.



MOOC on Diagnosing Rare Diseases: from the Clinic to Research and back
Third run from April 18th!

The third 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 French Foundation for Rare Diseases will start on April 18th. Registration is free and open at this link: https://www.futurelearn.com/courses/rare-genetic-disease

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

ERN Research Training Workshops

The ERN Research Training Workshops funding opportunity is open for applications until April 25th. The goal of the workshops is to train researchers and clinicians affiliated to ERN- Full Members or – Affiliated Partners in relevant topics on research in rare diseases. The costs for the workshop organization will be covered up to a limit of €25,000.
See https://www.ejpraregiseases.org/ern-research-training-workshop/

On this website you can find the currently open workshops for participants registration as well as the upcoming ones:
https://www.ejpraregiseases.org/our-actions-and-services/training-and-education/ern-workshops/
e.g. the workshop entitled “Comprehensive gene profiling, molecular tumor board (MTB) and artificial intelligence in the diagnosis and treatment of patients with rare adult cancers” aimed at increasing physicians’ awareness on the possibilities of comprehensive genomic profiling in gene-guided planning of modern cancer treatment and addressing multidisciplinary aspects between specialists who are working in ERN-EURACAN and ERN GENTURIS.

Ukraine: ERNs Helping Rare Disease Patients

The 24 ERNs have come together to launch a new website www.erncare4ua.eu to help rare disease patients affected by the war in Ukraine.
ERN GENTURIS is also supporting patients and their treating doctors especially those with NF1, NF2 or schwannomatosis (Thematic Group 1) who require urgent care.
See
https://www.genturis.eu/l=eng/Home.html

Solve-RD workshop: Navigating the Sandbox

On 19 May, Solve-RD will organise a workshop on the results of Solve-RD WP4 “Navigating the Sandbox”. The Sandbox is the place where Solve-RD data & results are being stored, shared and further (jointly) analysed. The workshop will provide an update on Solve-RD Sandbox services/functions, and also consider future plans, needs and possibilities.
For more information and registration: see
https://solve-rd.eu/solve-rd-workshop-navigating-the-sandbox-2/

ECRD deadline for posters extended to 21st April

The deadline for poster submissions for the 11th European Conference on Rare Diseases & Orphan Products (ECRD) has been extended to 21 April: https://www.rare-diseases.eu/posters/. Authors submitting a 300-word abstract will be automatically entered into a lottery to win a free pass to attend the conference.
The ECRD will be held online from 27 June to 1 July 2022.

Upcoming webinar:

Tuesday 24 May 2022
Fátima Carneiro (Centro Hospitalar Universitário São João, Porto, Portugal)
Pathology of CDH1-related diffuse gastric cancer

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

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