

Newsletter November 2022



Webinar: Hereditary breast- and ovarian cancer, aspects on risk reducing measures and hormonal replacement – the gyne-oncologist's perspective

Wednesday 9 Nov 2022, 16:00-17:00 CET

Dr. Angelique Flöter Rådestad
Karolinska Institutet, Stockholm, Sweden

Associate Professor Angelique Flöter Rådestad, Department for Womens and Childrens Health, Karolinska Institutet is a researcher within quality of life after cancer and prevention for breast- and ovarian cancer, especially in high risk individuals. Clinically she is a gyneoncologist with special focus on ovarian cancer and women with hereditary cancer. She is head of the hereditary cancer surveillance outpatient clinic at Karolinska University Hospital, Stockholm, Sweden.

This webinar will focus on risk reducing measures for individuals with BRCA mutation, benefits and risks of hormonal replacement at premature menopause after risk reducing salpingo-oophorectomy. Testosterone insufficiency and replacement will also be discussed. Further, ongoing translational research for medical prevention of breast- and ovarian cancer will be presented.

If you would like to attend this webinar, please register here:
<https://attendee.gotowebinar.com/register/7573554163881941260>



Webinar: Childhood cancer and genetic tumour risk syndromes – the geneticist's perspective

Wednesday 23 Nov 2022, 16:00-17:00 CET

Dr. Ann Nordgren
Karolinska Institutet, Stockholm, Sweden

Ann Nordgren is Senior consultant and Professor in Clinical genetics at Gothenburg University and Karolinska Institutet. She is coordinator of a large prospective national study "Genomic Medicine Sweden Childhood Cancer Predisposition" offering whole genome sequencing (WGS) to all children diagnosed with cancer in Sweden irrespective of diagnosis.

Genetic predisposition is the most common known cause of cancer in childhood and has to date been described in 5-15% of cancer cases in childhood. The advent of Massive Parallel Sequencing has led to increased knowledge about childhood cancer predisposition and the number of childhood cancer predisposing syndromes and cancer associated genes is steadily increasing.

This webinar will focus on childhood cancer predisposition and clinical benefits to individual patients when implementing WGS in the routine diagnostics for pediatric cancer.

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

<https://register.gotowebinar.com/register/7952492050301934862>

Upcoming webinars

25-01-2023

Stefan Aretz

Genetics 30 years after the discovery of APC

06-2-2023

Chella van der Post

Hereditary gastrointestinal cancer – the pathologist's perspective

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



ERN Coordinators Group meeting with DG SANTE in Brussels

On 4 October 2022 the ERN Coordinators Group met in Brussels. It was the first meeting in person since the beginning of COVID-19 pandemic. Prof Nicoline Hoogerbrugge (ERN GENTURIS Coordinator) and Nicoline Geverink (ERN GENTURIS project manager) represented ERN GENTURIS. Topics discussed with the European Commission were the accomplishments, challenges and future funding of the ERNs. An internal EC reorganisation means that a whole new team in EC DG SANTE will be dealing with the ERNs. The physical location of this team will move from Brussels to Luxembourg.

**FREE MOOC
DIAGNOSING RARE DISEASES:
FROM THE CLINIC TO RESEARCH AND BACK**

UPDATE



**Meet the expert teachers from the free course
Diagnosing Rare Diseases: from the Clinic to Research and back**

Mentors and educators, experts in the field, are actively present on the platform to answer the students' questions between 19 September and 3 December 2022. Take the opportunity to interact with them!

See <https://www.ejprarediseases.org/upcoming-update-on-mooc-diagnosis-rare-diseases-from-the-clinic-to-research-and-back/>

This course is organized within EJP-RD by ERN GENTURIS member Chrystelle Colas, ERN ITHACA member Laurence Faive, and EURORDIS director Roseline Favresse.

Registration is still possible via: <https://www.futurelearn.com/courses/rare-genetic-disease>
We specifically encourage medical and biomedical science students to register and follow the MOOC.

EJP RD

**28-29 November 2022
Online**

ejprarediseases.org

Rare Diseases Training

Biobanking in rare diseases: the Poland experience

The European Joint Programme on Rare Diseases is an initiative that has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement N°825575.

A free EJP-RD training on "Biobanking in rare diseases: the Poland experience" will take place online on 28-29 November 2022. The training is dedicated to scientists in the biomedical sector who want to learn about biobanking standards in Rare Disease research.

Registration deadline: 10 November 2022. More information:

<https://www.ejprarediseases.org/event/ejp-rd-training-biobanking-in-rare-diseases-the-poland-experience/>

Last chance to apply for an ERN Research Mobility fellowship

The last call is still open until 13 November 2022.

See <https://www.ejprarediseases.org/ern-research-mobility-fellowship/>



Open on October 3rd, 2022
until November 13th, 2022

The ERN

Research Mobility Fellowship

funding opportunity

What can be funded?
Visits of junior clinical or lab researchers aimed to acquire scientific skills and advance rare disease research performed by the ERNs

Who can be funded?
PhD students, post-Docs and medical doctors from ERN Member/Affiliated Partner centers or other European research institutions

Where can you go?
- To another ERN Member/Affiliated Partner center
- To any research institution in Europe
Either home or host institution must be a Full Member or Affiliated Partner of an ERN

For how long can you go?
1 to 6 months



<https://www.ejprarediseases.org/ern-research-mobility-fellowship/>



<https://www.eurordis.eu.org/ern-research-mobility-fellowship/>

The aim of the call is in compliance with the vision and goals set by the International Rare Diseases Research Consortium (IRDIRC), which fosters international collaboration in rare diseases research



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