

Newsletter June 2023

Successful ERN GENTURIS meetings



ERN GENTURIS meeting in Glasgow, June 2023

ERN GENTURIS members and patient representatives met in Glasgow (Scotland, the UK) on 9-10 June 2023 to discuss the functioning of our ERN.

Some highlights of the meeting:

- Prof. Hoogerbrugge presented the goals of ERN GENTURIS for the upcoming years.
- Patient representatives shared their activities and involvement in the Network.



- Participants discussed ongoing evaluation, GENTURIS registry, guidelines development, research projects, communication and new CPMS.
- Dr Holm Graessner, Coordinator of ERN - RND and the chair of ERN Coordinators Group as of 1st July 2023, presented the future of the ERNs in the next 4 years.



ERN GENTURIS and ERN EURACAN symposium

A successful ERN GENTURIS and ERN EURACAN symposium took place on 26 May 2023 on Rare cancers and cancer syndromes in Helsinki, Finland.

Goals of this training: strengthening the cooperation of professionals from EURACAN and ERN GENTURIS networks and a joint discussion between patients and professionals.

The following professionals were among the speakers: Prof. Elke Holinski-Feder Germany, Prof. Wouter de Herder, Netherlands (EURACAN) and Dr. Maria Haanpää, Finland, Prof. Minna Pöyhönen and Dr. Outi Kuismin

EJP-RD/ERN Workshop

A successful EJP-RD ERN Workshop about “Psychological, molecular and administrative aspects of Hereditary breast and ovarian cancer genetic population screening (HBOC GPS)” organized by ERN GENTURIS member Arvids Irmejs from Pauls Stradins Clinical University Hospital took place on 27-28 April 2023 in Riga, Latvia.

35 delegates participated in this workshop.



ERN GENTURIS members Rolf Sijmons, Svetlana Lagercrantz, Hildegunn Høberg Vetti, Jan Lubinski and Richarda de Voer contributed to the programme.

Education opportunities:

Online-Symposium: Liquid Biopsy – ctDNA in colorectal cancer and beyond

On July 15th 2023 at 9:00 - 14:15 CEST a free online symposium entitled "Liquid Biopsy – ctDNA in colorectal cancer and beyond" organised by ERN GENTURIS member MGZ - Medizinisch Genetische Zentrum in München will be held via Zoom.

More information available on our website: <https://www.genturis.eu/l=eng/News-and-events/News-and-events.html>

Date and time: 15 July 2023 at 9:00 - 14:15 CEST

Cost: Free!

Certification: 5 CME-points

Diagnosing Rare Diseases: from the Clinic to Research and Back

Would you like to discover the role of research, clinical investigation and data sharing in diagnosing rare diseases? Join the online course: **Diagnosing Rare Diseases: from the Clinic to Research and Back**.

In the context of the European Joint Programme for Rare Diseases EJPRD, **co-developed by Chrystelle Colas (ERN GENTURIS) and Laurence Faivre (ERN ITHACA), the Foundation For Rare Diseases, and EURORDIS**, this Massive Open Online Course (MOOC) addresses the diagnostic research progress, types of genetic tests for rare diseases, and the impact of having or lacking a diagnosis on patients' lives.

The MOOC is **continuously open for enrollment and the access to the content is free for the first 5 weeks**.

For more information go to: <https://bit.ly/3W95OZN>



EJP RD – ERN

WORKSHOP

**CDH1 RELATED HEREDITARY
DIFFUSE TYPE GASTRIC CANCER:
THE SHIFT FROM PROPHYLACTIC
TOTAL GASTRECTOMY TO
OPTIMAL ENDOSCOPIC
SURVEILLANCE**

Organizer: Tanya Bisseling

12-13 OCTOBER 2023

Radboud university medical center
Nijmegen, Netherlands

ERN WORKSHOPS
THE EJP RD "ERN RESEARCH
TRAINING WORKSHOPS CALL"



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

Workshop on CDH1 Related Hereditary Diffuse Type Gastric Cancer

The registration for the upcoming ERN workshop, organized by ERN GENTURIS member Tanya Bisseling (Radboudumc) "CDH1 Related Hereditary Diffuse Type Gastric Cancer: the shift from prophylactic total gastrectomy to optimal endoscopic surveillance" is now open.

Calling all experts interested in exploring the psychological, molecular, and administrative aspects of CDH1-related hereditary diffuse type gastric cancer! This workshop will offer invaluable insights into the latest research findings and best practices in patient care.

 Registration is open from May 31st 2023 until July 15th 2023

Check our website for full info: <https://www.genturis.eu/l=eng/News-and-events/News-and-events.html>

ESMO
PRECEPTORSHIP



The ESMO Preceptorship on Hereditary Cancer Genetics 2023

The ESMO Preceptorship on Hereditary Cancer Genetics 2023 will be held on 29-30 September 2023 in Paris, France.

The course is co-chaired by ERN GENTURIS members Judith Balmaña and Nicoline Hoogerbrugge.

This accredited educational course is primarily aimed at oncologists resident in Europe, but application was open to all ESMO members.

More information is available here:

<https://www.esmo.org/meeting-calendar/esmo-preceptorship-on-hereditary-cancer-genetics-2023-paris>



Save the date 5th course in Hereditary Cancer Genetics, Bertinoro, Italy

This course, organised by members of the ERN GENTURIS, aims to deliver up-to-date knowledge on hereditary cancers to clinical and molecular geneticists in training or certified. Once the programme is available and registration opens, we

will inform you on our webpage, LinkedIn and via our ERN GENTURIS newsletter.

Date: 17-20 September 2024

Upcoming ERN GENTURIS webinars

06-09-2023

Lynch syndrome update

Prof. Elke Holinski-Feder

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

GENTURIS Registry up and running!

Read our special edition newsletter about creation of GENTURIS registry



This special edition newsletter is in celebration of the establishment of the GENTURIS registry.

This newsletter shows an impression of the GENTURIS registry and gives a tour along all developments.

Read more here: <https://lnkd.in/dCXK8wqd>



ERN GENTURIS

With every diagnosis we can help an entire family

Visit our [website](#) and our [LinkedIn page](#)

This newsletter is sent to katarzyna.urbanczyk@radboudumc.nl
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