ERN GENTURIS

TUMOUR PREDISPOSITION CONFERENCE
FEBRUARY 10 + 11, 2022

European Reference Network
for rare or low prevalence complex diseases

Network
Genetic Tumour Risk Syndromes (ERN GENTURIS)

genturis2022.eu

Dear friends and colleagues,

On February 10th and 11th of 2022, ERN GENTURIS,
the European Reference Network on Genetic Tumour Risk Syndromes,
will celebrate its 5-year anniversary with a
free online conference.
You are all cordially invited to attend.

The conference will feature updates on the ERN GENTURIS tumour predisposition syndromes, reports on special ERN GENTURIS projects and patient perspectives. It will also include a half-day introductory educational session specially aimed at health care professionals who wish to learn the basics of hereditary cancer predisposition.

with kind regards,
the organising committee:
Gareth Evans, Hildegunn Høberg, Judith Balmaña,
Rita Magenheim and Rolf Sijmons

For registration (free)
please visit our website
genturis2022.eu
a certificate of attendance will be provided after the sessions

Contact: genturis@radboudumc.nl

Anne Charpentier designed the conference logo: the 'Trinity Knot' symbolizes power, hope and courage necessary to cure illnesses. The blue snake is the international symbol of medicine

Program Thursday, February 10, 2022

Educational session

(chair: Hildegunn Høberg Vetti)

08.45-09.00 Welcome. What is ERN GENTURIS?
Nicoline Hoogerbrugge

09.00-09.30 General introduction: when to suspect hereditary cancer and why is that important?
Maurizio Genuardi

09.30-10.00 Hereditary breast and ovarian cancer
Svetlana Bajalica Lagercrantz

10.00-10.15 Break

10.15-10.45 Hereditary colorectal cancer and polyposis
Elke Holinski-Feder

10.45-11.15 Syndromic and rare genetic tumour risk disorders
Rolf Sijmons

11.15-12.00 Questions & Answers: meet the experts

Program Thursday, February 10, 2022

Scientific Session 1

(chair: Judith Balmaña)

14.00-14.05 Introduction to the 2022 celebration conference of 5 year ERN GENTURIS
Rolf Sijmons

14.05-14.20 ERN GENTURIS. Goals and 5-year retrospective
Nicoline Hoogerbrugge

14.20-14.35 Genetic tumour risk syndromes in Europe: patient perspective
Tamara Hussong-Milagre

14.35-14.50 Organizing hereditary cancer healthcare in a small country
Mateja Krajc

14.50-15.05 ERNs from a European Commission perspective
Martin Dorazil

15.05-15.30 Questions & Answers

15.30-16.00 Break

Scientific Session 2

(chair: Svetlana Bajalica Lagercrantz)

16.00-16.15 Breast cancer predisposing genes: BRCA1/2 and beyond
Chrystelle Colas

16.15-16.30 Therapeutic implications of germline genetic variants 'in the real world'
Hans Petter Eikesdal

16.30-16.45 High prevalance of genetic tumour risk syndromes in general population
Janet Vos

16.45-17.00 Challenges in rare syndromes with variable expressivity: example of hereditary paraganglioma
Eamonn Maher

17.00-17.30 Questions & Answers

Program Friday, February 11, 2022

Scientific Session 3

(chair: Kathleen Claes)

09.00-09.15 Universal MSI testing: identification of Lynch syndrome and therapeutic opportunities
Marjolijn Ligtenberg

09.15-09.30 Searching new genes for CRC and polyposis in SOLVE-RD: an ERN GENTURIS project
Stefan Aretz

09.30-09.45 The CDH1 and other familial gastric cancer genotype-phenotype associations: an ERN GENTURIS project
Carla Oliveira

09.45-10.00 Cancer risk in PHTS: an ERN GENTURIS project
Linda Hendricks

10.00-10.30 Questions & Answers

10.30-11.00 Break

Scientific Session 4

(chair: Maurizio Genuardi)

11.00-11.15 Neurofibromatosis: changes to diagnostic criteria
Gareth Evans

11.15-11.30 Neurofibromatosis: patient's perspectives
Claas Röhl

11.30-11.45 Searching for new genes for phaeochromocytomas: an ERN GENTURIS project
Evelin Schröck

11.45-12 00 How to develop ERN guidelines? The ERN GENTURIS experience
Matt Bolz-Johnson

12.00-12.30 Questions & Answers

12.30-12.45 Break

Program Friday, February 11, 2022

Scientific Session 4 (continued)

(chair: Maurizio Genuardi)

12.45-13.15 Thierry Frébourg memorial lecture
'A life dedicated to Li-Fraumeni syndrome'
Stéphanie Baert-Desurmont, Gaëlle Bougeard and Edwige Kasper

13.15-13.30 GENTURIS: the next 5 years
Nicoline Hoogerbrugge

13.30 End of the conference

Faculty *(in alphabetical order)*

Stefan Aretz, clinical geneticist and professor for the Genetics of Familial Tumour Syndromes; Institute of Human Genetics, Medical Faculty, University of Bonn, and Center for Hereditary Tumor Syndromes, University Hospital Bonn, Germany

Stéphanie Baert-Desurmont, molecular geneticist, Department of Genetics, Rouen University Hospital and Inserm UMR 1245, Normandy Centre for Genomic and Personalized Medicine, Rouen, France

Svetlana Bajalica Lagercrantz, associate professor in Medical Genetics and senior consultant in Oncology and in Clinical Genetics, and the head of the Cancer Genetic Unit at Karolinska University Hospital, Stockholm, Sweden

Judith Balmaña, medical oncologist, hereditary cancer genetics group, medical oncology department, Hospital Vall d'Hebron, Barcelona, Spain

Matt Bolz-Johnson, specialist in the development of clinical networks for rare diseases, CEO and co-founder of Square Root Thinking, Köln, Germany

Gaëlle Bougeard, molecular geneticist, Department of Genetics, Rouen University Hospital and Inserm UMR 1245, Normandy Centre for Genomic and Personalized Medicine, Rouen, France

Kathleen Claes, clinical laboratory geneticist, professor and PI of CRIG (Cancer Research Institute Ghent), Center for Medical Genetics, Ghent University Hospital, Belgium

Chrystelle Colas, clinical geneticist, Genetic Oncology department, Hospital Curie, Paris, France

Martin Dorazil, deputy head of Unit B3 - European Reference Networks and Digital Health, European Commission, DG SANTE

Hans Petter Eikesdal, Consultant medical & radiation oncologist, Department of Oncology, Haukeland University Hospital & Professor, Department of Clinical Science, University of Bergen, Norway

Gareth Evans, clinical geneticist, professor of Medical Genetics and Cancer Epidemiology, The University of Manchester, Consultant in Medical Genetics and Cancer Epidemiology, Central Manchester Hospitals NHS Foundation Trust and The Christie NHS Foundation Trust

Maurizio Genuardi, clinical geneticist and professor of medical genetics, Department of Life Sciences and Public Health, Catholic University, and Medical Genetics Unit, Agostino Gemelli IRCCS University Hospital, Rome, Italy

Linda Hendricks, PhD candidate, department of Human Genetics, Radboud university medical center, Nijmegen, The Netherlands

Faculty, *continued*

Hildegunn Høberg-Vetti, clinical geneticist, Western Norway Familial Cancer Center, Haukeland University Hospital, Bergen, Norway

Elke Holinski-Feder, professor and clinical geneticist, Medizinische Klinik und Poliklinik IV, Campus Innenstadt, Klinikum der Universität München, MGZ – Medical Genetic Center Munich, Munich, Germany

Nicoline Hoogerbrugge, professor of hereditary cancer, department of Human Genetics, Radboud university medical center, Nijmegen, the Netherlands

Tamara Hussong Milagre, member ePAG Council ERN GENTURIS, president of the Portuguese patient organization "EVITA - Hereditary Cancer", Lisbon, Portugal

Edwige Kasper, molecular geneticist, Department of Genetics, Rouen University Hospital and Inserm UMR 1245, Normandy Centre for Genomic and Personalized Medicine, Rouen, France

Mateja Krajc, clinical geneticist and public health specialist, Cancer Genetics Clinic, Institute of Oncology Ljubljana, Ljubljana, Slovenia

Marjolijn Ligtenberg, clinical laboratory geneticist, clinical scientist in molecular pathology and professor molecular tumor genetics, department of Human Genetics and department of Pathology, Radboud university medical center, Nijmegen, The Netherlands

Eamonn Maher, clinical geneticist and professor of Medical Genetics and Genomic Medicine, head of the Department of Medical Genetics, University of Cambridge, U.K.

Carla Oliveira, molecular geneticist and group leader, i3S - Instituto de Investigação e Inovação em Saúde / Ipatimup - Institute of Molecular Pathology and Immunology University of Porto; Affiliated Professor, Department of Pathology, Faculty of Medicine, University of Porto, Porto, Portugal

Claas Röhl, patient representative, national patient organization NF Kinder (Austria), European umbrella organization of NF patient organizations NF Patients United (EU), European Patient Advocacy Group, European Reference Network on Genetic Tumour Risk Syndromes (ERN GENTURIS), Vienna, Austria

Evelin Schröck, professor of clinical genetics and head of the Institute for Clinical Genetics, Faculty of Medicine Carl Gustav Carus, TU Dresden, Dresden, Germany

Rolf Sijmons, clinical geneticist and professor of medical translational genetics, department of Genetics, University Medical Center Groningen, Groningen, the Netherlands

Janet Vos, epidemiologist & postdoctoral researcher at the department of Human Genetics, Radboud university medical center, Nijmegen, The Netherlands

What is ERN GENTURIS?

An European Reference Network (ERN) is a network connecting health care providers and centres of expertise of highly specialised healthcare, for the purpose of improving access to diagnosis, treatment and the provision of high-quality healthcare for patients with Rare Diseases no matter where they are in Europe. Patient representatives are involved in the governance of ERNs.

Genturis patients are at very high hereditary risk of developing common cancers, which are often located in multiple organ systems. In case they are diagnosed with cancer they need different treatment and follow-up as compared to non-hereditary cancers.

The aims of ERN GENTURIS are: improved identification of people living with a genetic tumour risk syndrome; reduced variation in clinical practice and outcomes; development of evidence based clinical guidelines; development and use of patient registries, biobanks and research studies; defined health care pathways to facilitate improved access to international specialist clinical knowledge for patients and their families living throughout the EU; pan-European Development and use of patient registries, biobanks and research studies.

ERN GENTURIS takes a family-based approach, focussing not just on the individual but also their relatives who may also be at risk given the hereditary nature of the conditions.

more information at genturis.eu

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