

Summer Institute: "Genetics, Ethics and Clinical Translation" 22-25th June 2010, Hotel Zuiderduin, Egmond aan Zee, The Netherlands



Objectives and target group

This four day intensive course is designed for professionals actively involved in biobanking who want to learn more about **ethical, legal and societal implications** related to the translation of epidemiological results from genetic and genomic research to clinical practice.



The Summer Institute offers insight about issues and solutions applicable to the field and gives participants the opportunity to interact with the lecturers through discussions and working group sessions. Some previous basic knowledge within ethics is recommended.

The program

The course will be organized into the following three sessions:

- Introduction to translational research and ethical, legal and societal issues in biobanking
- Implications of genetic testing, personal genome and personalized medicine
- Engaging stakeholders and society

The course will total 17 hours of teaching and work group sessions (breaks and summary not included).



The faculty

The faculty gathers world-known experts whose work reflects broad international experience.

- Bartha Maria Knoppers, Professor, McGill University, Canada
- Jennifer Harris, Senior researcher, Norwegian Institute of Public Health, Norway
- Richard Tutton, Senior Lecturer and Assistant Director, Lancaster University, UK
- Marta Gwinn, Associate Director, National Office of Public Health Genomics, Centers for Disease Control and Prevention, USA
- A. Cecile J.W. Janssens, Associate professor, Erasmus University Medical Center, The Netherlands
- Martina C Cornel, Professor, VU University Medical Center, The Netherlands
- Lidewij Henneman, Assistant professor, VU University Medical Center, The Netherlands
- Anne-Marie Tassé, Professional associate, McGill University, Canada
- Isabelle Budin Ljøsne, Adviser, Norwegian Institute of Public Health, Norway
- Heidi HC Howard, Postdoctoral fellow, Katholieke Universiteit Leuven, Belgium
- Dr Christine Patch, Guys Hospital, UK
- Jacqueline Broerse, Associate professor, VU University, The Netherlands
- Yann Joly, Assistant Professor, McGill University, Canada
- Denise Avard, Associate Professor, McGill University, Canada
- Frans van Dam, Head Communications, CSG, The Netherlands

PRELIMINARY PROGRAM – CHANGES MAY OCCUR

Tuesday 22nd June 2010

Session 1 - Introduction to Translational Research and ELSI issues in Biobanking (Room 558)	
Moderator: Cecile Janssens, Erasmus University Medical Center	
09.00	Welcome
09.15	Prospective/Retrospective Biobanking and Translational Research Jennifer Harris, Norwegian Institute of Public Health, Norway
10.00	Coffee break
10.15	Ethical, Legal and Societal Issues in Biobanking Bartha M Knoppers, McGill University, Canada
11.15	Coffee break
11.30	Biobanking and Public Health: Uses and ELSI Implications Marta Gwinn, National Office of Public Health Genomics, Centers for Disease Control and Prevention, USA
12.15	Lunch
13.30	Working Group Session: Case Study Session Chair: Bartha M Knoppers, McGill University, Canada
14.30	Coffee break
14.45	Expectations about the Future of Personal Genomics: Markets, Investors, Regulators and Users Richard Tutton, Lancaster University, UK
15.30 – 16.00	Discussion in plenum and wrap-up
19.00	Dinner

Wednesday 23rd June 2010

Session 2 - Towards Translation: Genetic Testing, Personal Genome and Personalized Medicine (Room 558)	
Moderator: Bartha M Knoppers, McGill University, Canada	
09.00	Introduction to Genetic Testing and Pharmacogenomics Cecile Janssens, Erasmus University Medical Center, The Netherlands
09.45	Coffee break
10.00	Genetic Screening: Policy, Organization and Update Martina Cornel, VU University Medical Centre, The Netherlands
10.45	Coffee break
11.00	Psychological and Behavioural Implications of Genetic Testing Lidewij Henneman, VU University Medical Centre Amsterdam, The Netherlands
11.45	Discussion in plenum
12.15	Lunch
13.30	Working Group Session: Case Study Session Chair: Cecile Janssens, Erasmus University Medical Center
14.30	Coffee break
14.45	Ethical, Legal and Societal Implications of Genetic Testing Anne-Marie Tassé, McGill University, Canada
15.30	Coffee break
15.45	In search for a balance between privacy protection and powering up the discovery Maria Kreystianinova, EMBL-EBI, UK
16.30-17.00	Discussion in plenum and wrap-up
20.30	Dinner at the beach restaurant “De Schelp”

Thursday 24th June 2010

Session 2 continues: Towards Translation: Genetic Testing, Personal Genomes and Personalized Medicine (Room 558)	
Moderator: Isabelle Budin Ljøsne, Norwegian Institute of Public Health, Norway	
09.00	Introduction to Commercial and Recreational Testing Cecile Janssens, Erasmus University Medical Center, The Netherlands
09.45	Coffee break
10.00	Ethical Aspects of Commercial and Recreational Testing Heidi Howard, Centre for Biomedical Ethics and Law, Belgium
10.45	Coffee break
11.00	Policy Aspects of Commercial and Recreational Testing Christine Patch, Guys Hospital, UK
11.45	Discussion in plenum
12.15	Lunch
	Afternoon: free time
20.00	Dinner

Friday 25th June 2010

Session 3 - Engaging Stakeholders and Society (Room 558)	
Moderator: Jennifer Harris, Norwegian Institute of Public Health	
09.00	Introduction to Interactions and Strategies Jacqueline Broerse, VU University Amsterdam, The Netherlands
09.45	Coffee break
10.00	Are the Respect for Privacy and Open Source Compatible? Yann Joly, McGill University, Canada
10.45	Coffee break
11.00	Working Group Session: How to Communicate Scientific Results to Stakeholders? Session Chair: Denise Avard, McGill University, Canada
12.00	Lunch
13.00	Working Group Session: Title to be confirmed Session Chair: Frans van Dam, CSG, The Netherlands
15.00 – 15.15	Wrap-up and evaluation



The organizing committee

The Summer Institute is jointly organised by:

- The ENGAGE Consortium (European Network for Genetic and Genomic Epidemiology – www.euengage.org)
- The Centre for Society and Genomics (www.society-genomics.nl)
- P³G - Public Population Project in Genomics (www.p3g.org)

Venue

The course will take place at the Hotel Zuiderduin, Egmond aan Zee, The Netherlands. The Hotel Zuiderduin is situated at the foot of the dunes and just 100 metres from the beach in the lively town centre of Egmond aan Zee. The town can be easily reached by train from Amsterdam and Schiphol airport.

Hotel Zuiderduin has 365 modern rooms. All rooms are equipped with bath / shower, toilet, multimedia television, telephone and Internet. In addition, all rooms have a private terrace or balcony.

For more information about the hotel: www.zuiderduin.nl

Registration

The course is free of charge for participants from ENGAGE partner institutions.

For participants from non-ENGAGE institutions, a registration fee of 200 Euros will apply. The fee will cover accommodation for 4 nights (check-in: 21st June – check-out: 25th June), catering and tutoring for the whole duration of the Summer Institute. The same conditions apply for participants from ENGAGE partner institutions.

All participants (from ENGAGE institutions and non-ENGAGE institutions) are requested to cover their travel fees to and from the course location themselves.

Participants from ENGAGE partner institutions who need financial support may apply for a travel bursary to the ENGAGE Exchange and Mobility Program. (Contact person: Adviser Isabelle Budin Ljøsne – email: isabelle.budin.ljosne@fhi.no)

To apply for the course, please fill in the application form and send it to Isabelle Budin Ljøsne, Norwegian Institute of Public Health.

E-mail: isabelle.budin.ljosne@fhi.no

Fax: +47 21 07 82 52

Deadline for applications (extended) : June 11th 2010

The number of places available at the course is limited. Early registration is recommended!