

2nd day: September 7, 2012

Part 3: Biobank Research and Epidemiology

- 9.00 - 9.30 Genome sequencing in epidemiological studies
Speaker: Camilla Stoltenberg, Norway
Chair: Peter Rehak, Austria
- 9.30 - 10.00 Ways of analyzing data that minimize predictive value and incidental findings?
- 10.00 - 10.15 Presentation of a population based project: Screening cancer patient genomes for mutations and germ line variation
Speaker: Ola Myklebost, Norway
Chair: Michael Fuchs, Germany
- 10.15 - 10.30 Coffee Break
- 10.30 - 11.15 Group session: Shared ethical debate
- 11.15 - 12.00 Plenary session:
Chair: Elmar Doppelfeld
- 12.00 End of the Conference
- 13.30 Lunch
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- 12.00 - 13.30 Internal Project Meeting
EURECNET: Proceedings and Next Steps
Chair: Dirk Lanzerath
- 13.30 Lunch
- 14.30 End of the Internal Project Meeting



EURECNET Conference:

Whole genome sequencing. Scientific, ethical and legal challenges for review by research ethics committees

**Oslo,
September 6-7, 2012**

Venue:
Holmen Fjordhotell
Slemmestadveien 64
1394 Nesbru (in the vicinity of Oslo)



1st day: September 6, 2012

8.30 - 8.50 **Welcome and introduction**

Gunnar Nicolayssen, chairman of the network of Norwegian REC
Dirk Lanzerath, coordinator of EURECNET
Elmar Doppelfeld, chairman of EUREC

Part 1:

Whole genome sequencing: Overview and perspectives

- 8.50 - 9.15 Understanding the science and technology of whole genome sequencing
Speaker: Dag Erik Undlien, Norway
Chair: Maria Alexandra Ribeiro, Portugal
- 9.15 - 9.45 Does whole genome sequencing raise new challenges for RECs? – Legal Perspectives
Speakers: David Townsend, The Netherlands and Mark Taylor, UK
Chair: Aime Keis, Estonia
- 9.45 - 10.15 Coffee Break
- 10.15 - 11.00 Does whole genome sequencing raise new challenges for RECs? – Ethical Perspectives
Speaker: Jakob Elster, Norway
Chair: Beatrice Ioan, Romania
- 11.00 - 11.30 Public perceptions and attitudes towards DNA sequencing
Speaker: Torben Hviid Nielsen, Norway
Chair: Vents Silis, Latvia
- 11.30 - 12.30 Lunch

- 12.30 - 13.00 RECs in Europe: Learning from each other

Speaker: Hugh Davis, UK
Chair: Knut Ruyter, Norway

Part 2: Clinical Genetic Research

- 13.00 - 13.30 Distinctions between genetic research and clinical genetic services
Speaker: Arvid Heiberg, Norway
- 13.30 - 13.45 Presentation of a project of clinical research: Next generation DNA sequencing
Speaker: Dag Erik Undlien, Norway
Chair: Eugenia Lamas, France
- 13.45 - 14.45 Group sessions: Shared ethical debate
- 14.45 - 15.15 Coffee Break
- 15.15 - 16.00 Plenary session
Chair: Josef Glaza, Slovakia
- 16.00 - 16.30 Genome Sequencing: Expectations of the EC Ethics review
Speaker: Dorian Karatzas, European Commission
Chair: Gisela Dahlquist, Sweden
- 16.30 - 17.30 Presentation of potential EUREC partners
Chair: Eugenijus Gefenas, Lithuania
- The system of RECs in Slovakia
Speaker: Jozef Glasa, Slovakia
- The system of RECs in Greece
Speaker: Ismini Kriari, Greece
- 18.00 Dinner



Speakers and Chair Persons in alphabetical order

Gisela Dahlquist Central Ethical Review Board, Stockholm, Sweden, Member of the EUREC Board

Hugh Davis M.D., Ethics Advisor, National Research Ethics Services, UK

Elmar Doppelfeld Permanent Working Party of Research Ethics Committees in Germany, Chair of EUREC

Jakob Elster Regional Committees for Medical and Health Research Ethics, South East Norway, University of Oslo

Michael Fuchs Institute for Science and Ethics, University of Bonn, Germany

Eugenijus Gefenas Lithuanian Bioethics Committee Vilnius, Lithuania, Vice-Chair of EUREC

Arvid Heiberg Professor of Genetics, Chairman of Regional Committees for Medical and Health Research Ethics, South East Norway, University of Oslo

Beatrice Ioan University of Medicine and Pharmacy „Gr. T. Popa“ Iasi, Romania

Jozef Glasa Institute of Medical Ethics and Bioethics, Bratislava, Slovakia

Dorian Karatzas Head of Ethics Review, EC

Aime Keis Research Ethics Committee, University of Tartu, Estonia

Ismini Kriari Professor of Constitutional Law at Panteion University, Greece

Eugenia Lamas Institut National de la Santé et de la Recherche Médicale, Inserm, Paris, France

Dirk Lanzerath German Reference Centre for Ethics in the Life Sciences, University of Bonn, Germany. Head of EUREC Secretariat

Ola Myklebost Department of Molecular Biosciences, University of Oslo, Head of the Norwegian Microarray Consortium

Torben Hviid Nielsen Professor of Social Sciences, University of Oslo, Norway

Peter Rehak Professor at the Medical University of Graz, Austria

Maria Alexandra Ribeiro National Ethics Committee for Clinical Research - CEIC, Lisboa, Portugal, Member of the EUREC Board

Knut W. Ruyter Regional Committees for Medical Research Ethic, University of Oslo, Member of the EUREC Board

Vents Silis Assistant Professor Riga Stradins University, Latvia

Camilla Stoltenberg Deputy Director General, Norwegian Institute of Public Health

Mark Taylor Lecturer in Law, University of Sheffield, UK

David Townend Associate Professor of Law, University of Maastricht, The Netherlands

Dag Erik Undlien Member of the National Committee for Medical and Health Care Research Ethics, Norway

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Local organisation and services provided by the Regional Committees for Medical and Health Research Ethics, South East Norway, University of Oslo
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