

**EUROPEAN SUMMER SCHOOL ON MEDICAL LAW AND BIOETHICS
ACADEMIC SESSION**

INTRODUCTION TO HEALTH LAW AND BIOETHICS IN EUROPE: GENETICS

Salle Jacques Pous Faculté de médecine 37 Allées Jules Guesde 31000 Toulouse (France)

PROGRAMME

Coordinated by Anne-Marie Duguet and Anne Cambon-Thomsen

Monday 4th July

9 am Health and human rights in Europe *Henriette Roscam Abbing (The Netherlands)* Why health law and bioethics: patients' perspective *Solvita Olsena (Latvia)*

2 pm Respect of privacy Professional secrecy and confidentiality in Europe and in the world *Andre Pereira (Portugal)* *Lukas Prudil (Czech Republic)* Privacy and Confidentiality: Global Perspectives on the Need to Balance Multiple Public Policies *Harris Dean.M (USA)*

Tuesday 5th July*

9 am- Genetic information and its legal dimension: *Tobias Van der Baumen (The Netherlands)*,

- Data protection, Data exchanges: *Jean Herveg/ Jean-Marc van Gysegem (Belgium)*,

2 pm - Ethical aspects of genetic databases: *Sue Povey (UK)* *Anne-Marie Duguet (France)*

- Genetic testing in multifactorial diseases *Anne Cambon-Thomsen (France)*

Wednesday 6th July*

9 am - Legal framework and ethical dimension of genetic tests for diagnosis *Samantha Leonard (UK)*, *Sophie Julia (France)*

- Predictive genetic tests in practice: a psychological and ethical perspective *Gerry Evers-Kiebooms (Belgium)*

2 pm

- Direct to consumer offers *Pascal Borry (Belgium)* Direct To Consumers' Paradoxes *Pascal Ducournau (France)*

Thursday 7th July*

9 am - Ethical aspects of human biological materials collections and biobanks in genetics *Emmanuelle Rial-Sebbag (France)* *Naima Haoulia (France)*

- Return of Research Results in Population Biobanks *Ma'n H. Zawati (Canada)*

2 pm - Ethical aspects of sequencing in research and in clinical contexts *Alexandra Soulier (France)*

- Return of survey on " Am I fine with having my genome sequenced and put in a database" performed in the framework of the GEUVADIS project and discussion about challenges of large scale sequencing *Anne Cambon-Thomsen, Alexandra Soulier (France)* *Gabrielle Bertier (Spain)*.

Friday 8th July (for a mixed audience of scientists and non scientists)*

Bioinformatics and Sequencing platforms of use in Europe for genetic research and diagnostics

The speakers are prepared to present for mixed audience of participants geneticists or not, interested in the technical and scientific aspects or/and in bioethical dimensions

9 am Bioinformatics resources at the European Bioinformatics Institute (EMBL-EBI):

- Genomics: A View from Hinxton *Xose M Fernandez (UK)*

11 am and pm : Next generation sequencing issues:

- 11am Clinical issues related to next generation sequencing (NGS) *Martijn Breuning (The Netherlands)*

2pm

- Next generation sequencing (NGS) approach to limb-girdle muscular dystrophies *Vincenzo Nigro (Italy)*

- NGS (next generation sequencing) -related informed consent issues *Helger Yntema (The Netherlands)*

***Sessions in collaboration with the teams of the European FP7 projects :**

TECHGENE (www.techgene.org), N° 223143, **GEN2PHEN** (www.gen2phen.org); N° 200754 **and GEUVADIS** (www.geuvadis.org) N°261123