ETHICAL ASPECTS OF EXOME AND WHOLE GENOME SEQUENCING STUDIES IN RARE DISEASES
TEL AVIV, 14 OF JANUARY 2013

OPENING SESSION

08:15 - 08:50  Registration
08:50 - 09:10  Welcome
Prof. Avi Israeli, Chief Scientist, Ministry of Health, Israel
Dr. Sophie Koutouzov, E-Rare Coordinator, INSERM, France
Dr. Zelina Ben-Gershon, Chief Scientist office, Ministry of Health, Israel

Exome and whole genome sequencing studies in rare diseases
chair: Prof. Béla Melegh, Hungary

09:10 - 09:40  Whole Exome / Whole Genome Sequencing (WES/WGS) - Review of the state of the art Prof. Thomas Meltinger, Germany

09:40 - 10:10  WES - in transition from research to the clinics
Prof. Orly Elpeleg, Israel

10:10 - 10:30  Coffee break

INFORMED CONSENT

THEME 1  What should be the nature of informed consent in an era of WES/WGS studies? chair: Prof. Rivka Carmi, Israel

10:30 - 11:00  Establishing the informed consent in the research/diagnostic lab
Dr. Vardit Ravitsky, Canada

11:00 - 11:30  Dealing with incidental findings Prof. Susan Wolf, USA

11:30 - 12:00  Consent of minors and incapacitated adults
Adv. Talia Agmon, Israel

12:00 - 12:30  Ethical aspects of informed consent Prof. Judith Sandor, Hungary

12:30 - 12:50  Questions / Panel discussion

12:50 - 14:00  Lunch

THEME 2  Archived samples and data chair: Prof. Amos Shapira, Israel

14:00 - 14:30  When is re-consent indicated for previously collected samples / data? Prof. Nils Hoppe, Germany

14:30 - 15:00  Principles of informed consent in biobanks
Dr. Emmanuelle Rial-Sebbag, France

15:00 - 15:30  Research on archived samples in WES/WGS studies
Prof. Ephrat Levy-Lahad, Israel

15:30 - 16:00  Coffee break

THEME 3  Ethical and legal aspects of WES/WGS at the European level
chair: Dr. Monica Ensini, France

16:00 - 16:30  Legal and regulatory frameworks for WES/WGS - state of the art at the European level Dr. Simon Woods, UK

16:30 - 17:00  European initiatives for unified informed consent
Dr. Tessel Rijgter, The Netherlands

17:00 - 18:00  Questions / panel discussion