

Meeting of the 20<sup>th</sup> National Ethics Councils (NEC) Forum – the European Group on Ethics in Science and New Technologies (EGE) – the National Italian Bioethics Committee (NBC) 18<sup>th</sup> - 19<sup>th</sup> November 2014, Rome, Italy

## **Italian Presidency of EU 2014**

|             | Tuesday, 18 <sup>th</sup> November 2014   |
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| 13.00-14.00 | <b>Registration</b> (* identity card is required) Meeting venue: Sala Polifunzionale, Via Santa Maria in via n. 37 (translation is available English/Italian and Italian/English) |
| 13.00-14.00 | Light lunch   |
| 14.00-14.15 | Welcome Address: Prof. Francesco Paolo Casavola, Chair of NBC   |
| 14.15-14.30 | Introduction to the Nec Forum  Dr. Isidoros Karatzas, Head of Ethics Sector, DG RTD, European Commission Prof. Laura Palazzani, Vice-chair of NBC, Member of EGE                  |
| 14.30-15.00 | No Borders: The Importance of International Collaboration in Bioethics Prof. James Wagner, Vice-chair of the U.S. Presidential Commission for the Study of Bioethical Issues      |
| 15.00-15.20 | Introduction and chair:<br>Prof. Julian Kinderlerer, Chair of EGE   |
| 15.20-15.40 | EGE Opinion on Security and Surveillance Technologies  Dr. Siobhan O'Sullivan, Member of EGE, Chief Bioethics Officer of the National Advisory Committee on Bioethics, Ireland    |
| 15.40-16.15 | Coffee break  |

# **Biological and Health Data: Ethical and Legal Issues**

| 16.15-16.30 | Introduction and chair: Dr. Christiane Druml, Chair of the Austrian Bioethics Commission                  |
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|             | Dr. Christiane Drumi, Chair of the Austrian Bioethics Commission  |
| 16.30-16.50 | The New Data Protection Regulation  Dr. Caroline Gans Combe, Chair of the DG RTD Research Ethics Group on |
|             | the Data Protection   |
| 16.50-17.10 | Direct-to-consumer Genetic Tests and Biological Samples   |
|             | Dr. Vasiliki Mollaki, Scientific Associate of the Hellenic Bioethics Commission                           |
| 17.10-17.30 | Paediatric Biobanks   |
|             | Prof. Lorenzo d'Avack, Deputy Vice-chair of NBC   |
| 17.30-17.50 | Personal Data and Biological Samples: New Challenges  |
|             | Prof. Peter Dabrock, Vice-chair of the German Ethics Council, Member of EGE                               |
| 17.50-18.40 | Discussion  |
| 20.00       | Gala Dinner Villa Madama  |

|            | Wednesday, 19 <sup>th</sup> November 2014   |
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|            | Meeting venue: Sala Polifunzionale, via Santa Maria in via n. 37  Research Culture and Research Integrity: Ethical Challenges |
| 9.00-9.15  | Introduction and chair: Prof. Cinzia Caporale, Member of NBC and National Research Council                                    |
| 9.15-9.30  | Research Misconduct Prof. Kjell Asplund, Chair of the Swedish Council on Medical Ethics                                       |
| 9.30-9.45  | Research Culture  Dr. Hugh Whittall, Director of the Nuffield Council on Bioethics  |
| 9.45-10.00 | Research Transparency Prof. Jonathan Montgomery, Chair of the Health Research Authority                                       |

| 10.00-10.15 | Replication of Research Results  Prof. Kenneth Goodman, Director, University of Miami Bioethics Program   |
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| 10.15-10.30 | Rights and Duties for Researchers and Sponsors  Prof. Linda Nielsen, Vice-chair of EGE, Vice-chair of Unesco Intergovernmental Bioethics Committee  |
| 10.30-10.45 | Building Research Culture: Future Perspectives  Prof. Patrick Gaudray, Member of the French National Consultative Ethics  Committee for Health and Life Sciences  |
| 10.45-11.15 | Discussion  |
| 11.15-11.45 | Coffee break  |
|             | Ethics and Neurosciences  |
| 11.45-12.00 | Introduction and chair: Prof. Lucetta Scaraffia, Member of NBC  |
| 12.00-12.20 | Human Brain Project in Europe: Ethical Aspects Prof. Christiane Woopen, Chair of the German Ethics Council  |
| 12.20-12.40 | Ethics and Neuroscience: the Question of Free Will Prof. Jean-Claude Ameisen, Chair of the French National Consultative Ethics Committee for Health and Life Sciences   |
| 12.40-13.30 | Discussion  |
| 13.30-14.30 | Lunch   |
| 14.30-15.00 | An Update of European Activities Chair: Prof. Eugenijus Gefenas, Director of the Lithuanian Bioethics Committee Dr. Laurence Lwoff, Head of Bioethics Unit Secretary of the Committee on Bioethics (DH-BIO), Council of Europe Dr. Jim Dratwa, Head of the Scientific Secretariat of EGE, European Commission |
| 15.00-15.10 | Introduction to the NEC Working Groups Prof. Vicente Bellver Capella, Member of the Spanish Bioethics Committee   |
| 15.10-16.50 | NEC Working Groups Working Group 1: Citizenship and Science Introduction and coordination:  |

Prof. Monica Toraldo di Francia, Member of the Italian Bioethics Committee (Sala Polifunzionale)

#### Working Group 2: Ethics in Education

Introduction and coordination:

Dr. Isidoros Karatzas, Head of Ethics Sector, DG RTD, European Commission Prof. Vasileios Fanaras, Director 2<sup>nd</sup> Gymnasium of Thessaloniki, Greece, (Sala Monumentale)

#### Working Group 3: Delivery of Health Care and Robotics

Introduction and coordination:

Dr. Lotta Eriksson, Swedish Council of Medical Ethics Dr. Joana Namorado, EU Commission, NTD (Hall No. 5053A, 5<sup>th</sup> floor, Building entrance from Largo Chigi)

#### 17.00-17.50 Coordinators Report back to Plenary

(Sala Polifunzionale)

#### 17.50-18.10 Conclusion of the NEC

Dr. Isidoros Karatzas, Head of Ethics Sector, DG RTD, European Commission

### 18.10-18.30 Closing Remarks of the 20<sup>th</sup> NEC Forum

Prof. Stefano Semplici, Chair of the International Bioethics Committee of UNESCO

#### **18.45** Dinner (*Sala monumentale*)

#### **STEERING COMMITTEE:**

- Dr. Isidoros Karatzas, Head of Ethics Sector, DG RTD, EU Commission
- Prof. Laura Palazzani, Vice-chair of the National Bioethics Committee, Italy
- Dr. Siobhan O'Sullivan, Chief Bioethics Officer of the National Advisory Committee on Bioethics, Ireland
- Prof. Ioannis Papadimitriou, Former Chair of the Hellenic National Bioethics Commission, Greece
- Prof. Kjell Asplund, Chair of the Swedish Council on Medical Ethics, Sweden
- Prof. Jonathan Montgomery, Chair of the Nuffield Council, United Kingdom