



**Brocher Foundation workshop, Switzerland
December 5 – 7, 2007**

**“Translational medicine and public health policy: lessons from biobanks
Ethical, Legal, Social Issues (ELSI)”.**

**Chair : Anne Cambon-Thomsen, Toulouse, France –
Co-chairs: Bartha Maria Knoppers, Montreal, Canada; Jennifer Harris, Oslo, Norway**

Workshop Programme

December 5, 2007, from 18.00: Get together at Hotel Longemalle followed by diner at 20.00.

December 6, 2007

- 8:30-9:00 **INTRODUCTION**
Welcome and introduction at Brocher Foundation
Philippe Ducor, Professor at Geneva University, Director of the
Interdisciplinary Masters in Life sciences Law and member of the Foundation
Brocher Scientific Council
Workshop Objectives, format, introductions of participants
Anne Cambon-Thomsen, France
- 9:00-10:00 **CONTEXTS REGULATORY FRAMEWORKS – Chair *Christina Sampogna***
(OECD, France)
Regulatory Frameworks (**Anthony Mark Cutter**, UK)
Interoperability (**Bartha Maria Knoppers**, Canada)
- 10:00-10:30 Discussion (Leader **Jane Kaye**, UK)
- 10:30-11:00 Coffee Break
- 11:00-12:00 **CONTEXTS ON CONSENT AND CULTURE – Chair *Nouzha. Guessous -***
Idrissi (Morocco)
Consent (**Jan Helge Solbakk**, UNESCO, Paris)
Population culture and genetic studies (**Paolo Gasparini**, Italy)
- 12.00 – 12.15 Communication by **Susan Wallace** (Canada) : Consent for international
access to data and samples
- 12:15-12:45 Discussion (Leader **Christina Sampogna**, OECD, Paris)
- 12.45-14:00 Lunch
- 14:00-16:00 **COMPLEX DISEASES AND DIFFERENTIAL CONSIDERATIONS.
EXAMPLES : CANCER - ALZHEIMER’S DISEASE – IMMUNE DISORDERS – Chair:**
Angela Brand (Germany)

14:00-14:20 State of the Art in Cancer (**Pierre Hainault**, WHO, France)
14:20-14:40 State of the Art in Alzheimer disease (**Jean-Charles Lambert**, France)
14:40-15:00 Susceptibility and protective genes in immune disorders (**Erik Thorsby**, Norway)
15.00 – 15.30 Discussion: (Leader: **Bartha Maria Knoppers**, Canada)
15:30-16:00 Coffee Break

16.00 – 17.30 : **ELSI ISSUES IN TRANSLATIONAL MEDICINE AND BIOBANKS FROM VARIOUS EXPERIENCES.**

4 talks of 15 min + 30 min general discussion; discussion leader: **Anne Cambon-Thomsen**

Chair: Dominique Sprumont (Switzerland)

Presentations in this session will be given by the following young investigators

Deborah Mascalzoni (Italy) : Consent as a Multiple Step Process

Emmanuelle Rial-Sebbag (France) : From medical biobanks to research tools: new opportunity offered from the French legal perspective

Naomi Hawkins (UK) : *Human gene patents and translational research in genetic diagnostics*

María Almeida (Spain) : The Spanish National DNA Bank

17.30 – 17.50 Summing up day 1: **Jennifer Harris** (Norway)

December 7, 2007

8:30-10.00 BIOREPOSITORIES (Chair: *Carol George, UK*)

- 8:30 - 8.50 Biorepository: NCI guidelines (**Carolyn Compton**, USA)
8.50 – 9.10 Public health issues and biobanks **Angela Brand**, Germany)
9.10 – 9.40 Two communications (15 min each) by the following young investigators
Catherine Heeney (UK) Genetic Databases and the Assessment of Public Health Benefits
Eleni Zika (Spain) Biobanking in Europe – prospects for networking
9.40 – 10.10 Discussion (Discussion leader: **Kurt Zatloukal**, Austria)

10.10 – 10.35 : Coffee break

10.35 – 12.30 : RISK COMMUNICATION, PUBLIC ATTITUDES AND PUBLIC CONSULTATION (Chair: *O. Guillod (Switzerland)*)

10.35 – 10.55 Public understanding of susceptibility (*speaker to be replaced*)

10.55 – 11.15 Biobanking and "the public": a social science perspective (**Mary Dixon-Woods**, UK)

11.15 – 12.00 Three communications (15 min each) by the following young investigators
Carolyn Tarrant (UK) : Trust and confidence in biobank research: lessons from qualitative studies of participants

Pierre Antoine Gourraud (France) : « Sampling chromosomes » challenges the "individual informed consent"

Ninette Rothmueller (UK) : Issues for ethics steering committee of GEHA (Genetics of Healthy Aging), large EU biobank project to study the genetic determinants of human longevity

12.00 – 12.30 Discussion (leader: **Carol George**, UK)

12.30 – 14.00: Lunch

14.00 - 15.30 **CONCLUSION** – Chair: **Jan Helge Solbakk** (UNESCO, Paris)

14:00-14:30 Lessons learned: From population biobanks to biorepositories and the reverse (**Jennifer Harris**, Norway)

14:30-15:00 General Conclusions, summing up and perspectives (**Kurt Zatloukal**, Austria))

15:00-15:30 Final discussion and publication perspectives (**Anne Cambon-Thomsen**)

15:30 Tea and adjourn