



**COST Action - ISI303**  
**Citizen's Health through public-private Initiatives:**  
**Public health, Market and Ethical Perspectives**  
**(CHIP ME).**



**COST Action - BM1204**  
**An integrated European platform for pancreas**  
**cancer research: from basic science to clinical**  
**and public health interventions for a rare**  
**disease.**



**2015 CHIP ME - EUPancreas SUMMER SCHOOL**

**"Health, Genomics and Ethics:**  
**Current research, controversies and public policy-making"**

**Aegina Island, Greece - 10th-15th September 2015**



COST is supported by the EU  
Framework Programme Horizon 2020

## **Organizing committee**

George P. Patrinos, Patras, GR – CHIP ME WG2

Angela Brand, Maastricht University, NL – EUPancreas WG4

Oliver Feeney, NUIG, IR – CHIP ME WG3

Heike Felzmann, NUI Galway, IE – CHIP ME WG3

Michele Loi, Uni Minho, PT – CHIP ME WG2

Milan Macek Jr, Charles University, CZ – CHIP ME WG2

Núria Malats, CNIO, SP – EUPancreas WG4

Pierre Mallia, Uni. Malta, MT – CHIP ME WG3

Debora Mascalzoni, Uppsala, SE – CHIP ME WG1

Christina Mitropoulou, Athens, GR – CHIP ME WG2

Jan Helge Solbakk, Uni Oslo, NO – CHIP ME WG3

## SCIENTIFIC PROGRAM

### 10th September: Day 1 Afternoon

Session 1 Welcome & Introduction: *Translating genomic research to genomic medicine: setting the scene*

- Elia Stupka, Boehringer Ingelheim – *State of the art on the interface of genomic research and medicine*
- Jan-Helge Solbakk, University of Oslo – *Hype, hope and uncertainty in genomic medicine*

### 11th September: Day 2: Morning

Session 2: *Direct to consumer genetic testing: scientific and legal concerns*

- Christiana Pavlidou, University of Patras – *The science of DTC genetic/genomic testing: opportunities and limitations*
- Louiza Kalokairinou, K.U. Leuven – *The European legal framework on DTC genetic testing*

**13:00-14:30h Lunch break**

### 11th September: Day 2: Afternoon

Session 3: *DTC genetic testing, incidental findings and informed consent*

- Louiza Kalokairinou, K.U. Leuven – *Ethical considerations regarding DTC genetic testing*
- Leigh Jackson, Plymouth University – *Incidental findings in genetics: science, medicine and stakeholder perspectives*
- Heike Felzmann, NUI Galway – *Interactive session: The informed consumer in DTC genetic testing*

### 12th September: Day 3: Morning

Session 4: *Genomics in developing countries*

- Ron van Schaik, Erasmus MC – *Pharmacogenomics in developing countries*
- Jan-Helge Solbakk, University of Oslo – *Ethical issues relating to genetic diversity*

**13:00-14:30h Lunch break**

### 12th September: Day 3: Afternoon

#### Session 5: Genomics, markets and justice/inequality

- Michele Loi, UMinho – *Between philosophical ethics and the real world: can genomics cause injustice?*
- George P. Patrinos, University of Patras – *Community involvement, informed consent and knowledge sharing in public health genomic research in developing countries*
- Michele Loi, UMinho – *Interactive session: Social justice dilemmas in genomics*

### 13th September: Day 4: Morning

Poster session: Brief plenary presentation, followed by open poster session

**13:00-14:30h Lunch break**

### 13th September: Day 4: Afternoon

#### Session 6: Intellectual property in genomics

- Julian Cockbain, Erasmus University Medical Center – *Intellectual property law in genomics*
- Sigrid Sterckx, Ghent University – *The ethics of patenting in genetics*
- TBA - *Interactive session: Intellectual property in genomics: between promise and problems*

### 14th September: Day 5: Morning

Session 7: Public engagement and health care professionals' responsibilities:

- TBA - *Public engagement and genetic literacy*
- Alessio Squassina, University of Cagliari; George P. Patrinos, University of Patras - *Interactive session: The responsibilities of non-geneticist health professionals.*

**13:00-14:30h Lunch break**

### 14th September: Day 5: Afternoon

Free afternoon for Summer School Trainees

**14:30-16:00 CHIPME member meeting**

## 15th September: Day 6: Morning

Session 8: Public-private challenges in health research: The example of Pancreas cancer research

### 09:30-09:45h Welcome from

- COST Action CHIP ME Coordinator WG2: George P. Patrinos, University of Patras, Patras/Greece
- COST Action Chair EUPancreas, Núria Malats, CNIO, Madrid/Spain
- COST Action EUPancreas Coordinator WG4 and COST Action CHIP ME Coordinator WG2: Angela Brand, Maastricht University, Maastricht/Netherlands

09:45-10:15h Núria Malats, CNIO, Madrid/Spain - *Activities of the COST Action EUPancreas*

10:15-10:45h Ralf Sudbrak, Max Planck Institute for Molecular Genetics (MPIMG), Berlin/Germany - *Public-private challenges in pancreas cancer research I*

10:45-11:15h Sebastian Allais/Kamel Djazouli, Celgene, Switzerland/France - *Public-private challenges in pancreas cancer research II*

11:30-12:00h Andrew Biankin, University of Glasgow, Glasgow/UK - *Public-private challenges in pancreas cancer research III*

12:00-13:00h Discussion

13:00-14:30h Lunch break

## 15th September: Day 6: Afternoon

Session 9: Public-private challenges in health policy making: The example of pancreas cancer policy

14:30-15:00h Angela Brand, Maastricht University, Maastricht/Netherlands - *Public-private challenges in pancreas cancer policy I*

15:00-15:30h Bonnie Wolff-Boenisch, Science Europe, Brussels/Belgium - *Public-private challenges in pancreas cancer policy II*

15:30-16:00h Denis Horgan, European Alliance for Personalised Medicine (EAPM), Brussels/Belgium - *Public-private challenges in pancreas cancer policy III*

Session 10: Public-private challenges in health practice: The example of pancreas cancer practice

16: 15-16: 45h Lada Leyens, UNU-MERIT, Maastricht University, Maastricht/Netherlands - *Public-private challenges in pancreas cancer practice*

16:45-17:30h Discussion and close of summer school