## CO-ORGANIZERS

Public Health Agency of Canada

Agence de santé publique du Canada

# FINAL PROGRAMME

## SUNDAY, JUNE 4TH 2006

2:30 PM **Satellite Meeting**
Stichting Porticus Scholarship Programme *(Grantees Meeting)*
7:00 PM Registration and Opening Reception

8:15 PM **Keynote Address: Francis S. Collins (USA)**
*Genomic Medicine: Opportunities and Responsibilities*

## MONDAY, JUNE 5TH 2006 / NEWBORN SCREENING REVISITED

7:30 AM **Registration** / Breakfast

### I / EXPANSION OF SCREENING ?

8:30 AM Chair: Gerard Loeber *(Netherlands)*
8:40 AM Speaker: Bridget Wilcken *(Australia)*
*Expansion of Newborn Screening: Current Achievements and New Prospects*
9:00 AM Speaker: Nikki Kerruish *(New Zealand)*
*Newborn Screening for Genetic Susceptibility: What's the Harm?*
9:20 AM Speaker: Anne Marie Comeau *(USA)*
*Newborn Screening: The Massachusetts Model for Surveillance Research*
9:40 AM Discussion
10:10AM **Nutrition Break**

### II / NEWBORN SCREENING : CARRIER STATUS ?

10:40 AM Chair: Wylie Burke *(USA)*
10:50 AM Speaker: Helena Kääriäinen *(Finland)*
*Carriers Detected by Neonatal Screening: A Clinical Geneticist's View*
11:10 AM Speaker: Jean-Louis Dhondt *(France)*
*Lessons from Sickle Cell and Cystic Fibrosis: France*
11:30 AM Speaker: Lainie F. Ross *(USA)*
*Lessons from Sickle Cell and Cystic Fibrosis: USA*
11:50 AM Discussion
12:15 PM **Buffet lunch**

### III / NEWBORN SCREENING : STORAGE AND ACCESS FOR RESEARCH ?

1:30 PM Chair: Ellen Clayton *(USA)*
1:40 PM Speaker: Jeffrey R. Botkin *(USA)*
*Ethical and Social Considerations in Research with Stored Bloodspots*
2:00 PM Speaker: Bent Norgaard-Pedersen *(Denmark)*
*The Danish Newborn Screening Programme: Routine and Research Uses*
2:20 PM Speaker: Denise Avard *(Canada)*
*Research and Surveillance in Canada*
2:40 PM Discussion
3:00 PM **Nutrition Break**
3:20 PM **Selected Poster Presentations**
4:30 - 6:00 PM **P3G Observatory Networking Reception**

## TUESDAY, JUNE 6TH 2006 / PUBLIC HEALTH GENOMICS

7:30 AM **Registration** / Breakfast

### I / TOWARDS PUBLIC HEALTH GENOMICS ?

8:30 AM Chair: Melissa A. Austin *(USA)*
8:40 AM Speaker: Ron Zimmern *(UK)*
*What Is it and Why Is it Important?*
9:00 AM Speaker: Angela Brand *(Germany)*
*Challenges for Public Health Genomics*
9:20 AM Speaker: Anne Cambon-Thomsen *(France)*
*Normal Human Genomic Variation and Public Health*
9:40 AM Discussion
10:10 AM **Nutrition Break**

### II / STATE POWERS AND PRIVACY

10:40 AM Chair: Timothy Caulfield *(Canada)*
10:50 AM Speaker: Mark Rothstein *(USA)*
*Privacy Considerations in Public Health Genomics*
11:10 AM Speaker: Darren Shickle *(UK)*
*Balancing Private and Public Interests in Policy*
11:30 AM Speaker: Ruth Chadwick *(UK)*
*State Powers and State Responsibilities?*
11:50 AM Discussion
12:15 PM **Buffet lunch**

### III / IMPLEMENTATION IN PUBLIC HEALTH

1:30 PM Chair: Ana Sánchez Urrutia *(Spain)*
1:40 PM Speaker: Muin Khoury *(USA)*
*Genomics and Public Health in the United States*
2:00 PM Speaker: Sian Griffiths *(Hong Kong)*
*Mainstreaming Public Health Genomics: A Community Perspective*
2:20 PM Speaker: Jane L. Halliday *(Australia)*
*Implementing Population Screening Programmes*
2:40 PM Discussion
3:00 PM **Nutrition Break**
3:20 PM **Selected Poster Presentations**
4:30 PM - 6:00 PM **GRAPH-Int Networking Reception**

## WEDNESDAY, JUNE 7TH 2006 / CURRENT APPROACHES AND FUTURE PERSPECTIVES

7:30 AM **Registration** / Breakfast

### I / THE ROLE OF INTERNATIONAL STAKEHOLDERS

8:15 AM Chair: Andrea Boggio *(UK)*
8:25 AM Speaker: Elettra Ronchi *(OECD)*
*From Genomic Research to Public Health Practice: International Policy Implications*
8:45 AM Speaker: Mylène Deschênes *(P3G)*
*Public Population Project in Genomics*
9:05 AM Speaker: Mohamed Karmali *(GRAPH-Int)*
*Genome-Based Research and Population Health International Network*
9:25 AM Speaker: Alastair Kent *(EGAN)*
*Patients as Partners*
9:45 AM Discussion
10:05 AM **Nutrition Break**

### II / THE ROLE OF CITIZENS IN PUBLIC HEALTH GENOMICS

10:20 AM Chair : Michèle Jean *(Canada)*
10:30 AM Speaker: Hubert Doucet *(Canada)*
*Genomics and Modes of Democratic Dialogue: An Analysis of Two Projects*
10:50 AM Speaker: TBC
11:10 AM Speaker: Caroline Hurren *(UK)*
*Developments in Genomics: Engaging Young People*
11:30 AM Discussion
11:45 AM **Closing Address**: Bartha Maria Knoppers *(Canada)*
*Public Health Genomics: Responsibilities and Opportunities*

1:15 - 4:00 PM

### SATELLITE WORKSHOP/ CITIZEN ENGAGEMENT

Organized by GREB (Groupe de recherche en bioéthique, Université de Montréal)

Questions and challenges raised by mechanisms of citizen participation:
Implications for the development of policies for public health genomics? What places and roles for the citizen? What places and roles for the expert?

GENOMICS & PUBLIC HEALTH

4TH INTERNATIONAL DNA SAMPLING CONFERENCE
OMNI HOTEL, MONTREAL
JUNE 4-7, 2006

Please fill out this form on your computer before printing

## PERSONAL INFORMATION

Name _____

Institution _____

Address _____

City _____

Phone _____

State/Province _____

Zip/Postal Code _____

Country _____

Email _____

Fax _____

☐ Please do not include my name and adress in the participants list

## REGISTRATION FEES

**Indicate the sessions you would like to attend.**

# Before March 15, 2006: $375.
# After March 15, 2006: $450.
# Student Rate : $150.

☒ I am registering before March 15, 2006

☐ I am registering after March 15, 2006

☐ I will attend the reception on June 4th

☐ I will attend the P3G Networking Reception on June 5th

☐ I will attend the GRAPH-Int Networking Reception on June 6th

☐ I will attend the satellite workshop on June 7th

☐ I qualify for the student rate.
(Please send a proof of your student status)

**Total** ($CAD) 375

## PAYMENT

☐ Cheque (Payable to "CRDP - Université de Montréal")

or

Credit Card _____

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Cardholder Name _____

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