

# GM6: International efforts and opportunities in Genomic Medicine



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## Human Genomics and Personalized Medicine (E3)

Scientific Organizers: Kelly A. Frazer and Geoffrey S. Ginsburg

June 17–21, 2013

Clarion Hotel Sign, Stockholm, Sweden

*Organized in collaboration with Knut and Alice Wallenberg Foundation and Science for Life Laboratory - Stockholm. Sponsored by AstraZeneca, Boehringer Ingelheim Pharmaceuticals, Inc., H3 Biomedicine Inc., Nestlé Institute of Health Sciences and Onyx Pharmaceuticals, Inc.*

- Total attendance > 250
- > 30 countries

# Why this topic?

- Genomic medicine is global
- Genome 'hubs': US, India, China, Japan, Korea, Canada
- There is currently no global forum for genomic medicine
- Opportunities to lead and advance the genome sciences as a global agenda and to impact global health

# Some GM Activities Across the Globe

- Genome Canada - 2012 Large Scale Applied Research Projects in Genomics and Personalized Health
- Europe Science Foundation - Personalized Medicine and the European Citizen
- UK Human Genomics Strategy Group - Genomic Technology in Health Care
- The Israel National Inst for Health Policy Research - Personalized Medicine The Future is Here (But are we ready for it)?
- WEF - Global Agenda Council and Precision and Personalized Medicine

# Genome Canada and CIHR

- Genome Canada: To harness the transformative power of genomics to deliver benefits to Canadians
- “Genomics and Personalized Health” RFA
  - to support projects that will demonstrate how genomics-based research can contribute to a more evidence-based approach to health and improving the cost-effectiveness of the health-care system.
- \$67.5 million available
  - \$40 million through Genome Canada
  - \$22.5 million through CIHR
  - \$5 million from the Cancer Stem Cell Consortium
- At least 50% of funding through co-funding
- 17 projects funded in 2013

# The Israel National Institute for Health Research Policy

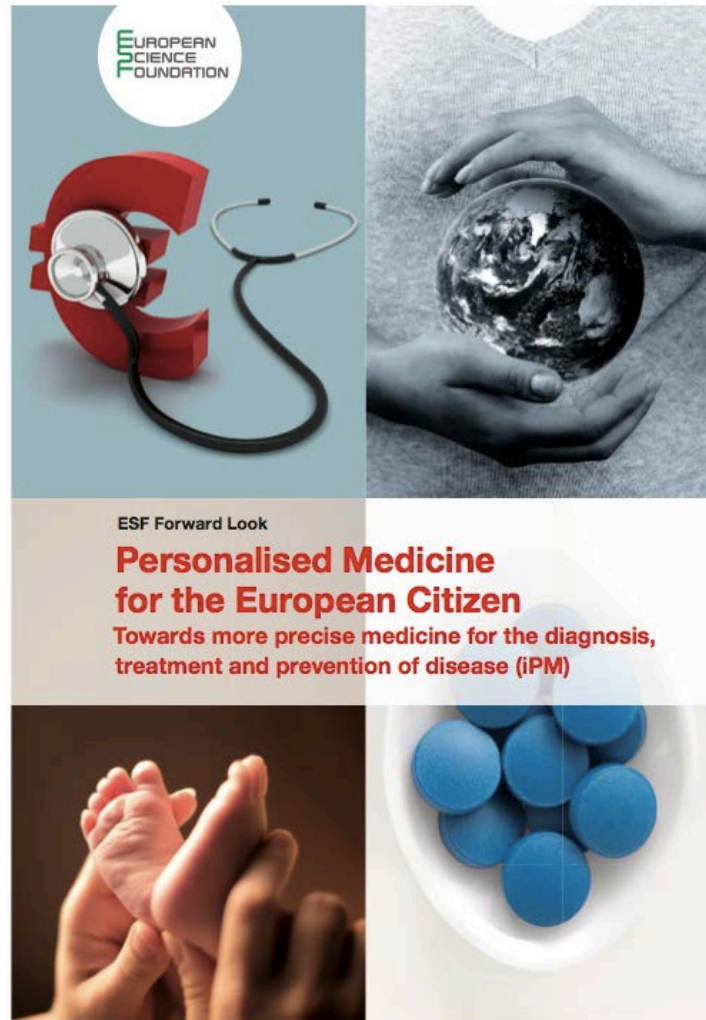
- International workshop Sept 2012
  - Assessment of genomic medicine technologies
  - GM and Health Economics
  - Bioethical and Legal Aspects of GM
  - Barriers in Implementation
- Output recommendations
  - Address the knowledge gap in health professionals
  - Data sharing and national data bank
  - Encourage collaborations
  - Ministry of Health to define priorities
  - Take advantage of Israeli health service structure (full coverage for all) and populations to promote proof of concept studies and evaluate outcomes

# UK Human Genomics Strategy Group

## January 2012

- A strategic vision for how the healthcare system in the UK can benefit from the mainstream adoption of genomic technology
- Successful translation of laboratory and academic research into quality-assured care pathways
- Developing a “service delivery infrastructure” that will enable equitable and affordable access to high quality genomic and genetic testing services
- Establishing the bioinformatics platform needed to underpin genomic and genetic testing and facilitate ongoing research
- Training the NHS and public health workforce of today and tomorrow
- Developing the policy agenda for the use of genomic data, and developing appropriate safeguards and processes to protect individuals
- Raise public awareness of genomic technology and how it can be used to benefit the care of patients across the NHS

# European Science Foundation





# The World Economic Forum

- Global Agenda Committee on Personalized and Precision Health – 2012
  - USA, India, Germany, Switzerland, UK, Singapore
- **Addressing the Economic Burden of Disease with PPH**
- **Accelerating the Science and Practice of Data Sharing for PPH**
- **Best practices in regulatory and reimbursement strategies for implementation of PPH**

# GM 6 Invitees

- USA
- UK
- Thailand
- Singapore
- Norway
- Netherlands
- Japan
- Israel
- Hungary
- Germany
- China
- Canada
- Belgium
- Africa ?
- Australia?
- South America?

# GM6 Draft Goals

- Identity common barriers, synergies and redundancy
- Identify common opportunities for implementation
- Identify common policy agenda
- Identify unique systems where it might be easier to get results (city state, single payer)
- Public private partnerships
- Economic analyses

## Some possible outcomes

- Develop an international convening organization
- International pilot projects
- Development of global standards (data capture, outcomes)
- International educational and workforce planning initiatives

<b>Components of GM Implementation Strategies</b>	<b>UK</b>	<b>Canada</b>	<b>Italy</b>	<b>ESF</b>	<b>CAP</b>	<b>IOM</b>	<b>AMA</b>
<b>Service delivery infrastructure for requesting and receiving genomic results</b>	X		X	X	X		
<b>Provider- and patient friendly, model genomic interpretive test reports and patient consultations</b>					X		
<b>Bioinformatics infrastructure for relating clinical characteristics to variants</b>	X	X	X	X	X	X	X
<b>Data sharing in accessible research databases</b>	X			X	X		X
<b>Standardized phenotypic, patient, variant, and reference information</b>	X			X	X	X	X
<b>Assessment of health economics and cost-effectiveness</b>	X	X	X		X	X	X
<b>Evidence of clinical validity and utility</b>	X	X	X	X	X	X	X
<b>Consent model</b>	X			X			X
<b>Training/workforce development</b>	X		X	X	X		
<b>Ethical and legal framework to protect against potential abuses</b>	X	X			X		X
<b>Engaging public and building awareness</b>	X	X	X	X			
<b>Genomics-based risk stratification and communication</b>		X	X				
<b>Genomics-based drug development, selection, and repurposing</b>		X	X			X	
<b>Genetic test regulation or registration</b>			X		X		X
<b>Regulatory frameworks adapted to changes in disease taxonomy and new diagnostic categories</b>				X			
<b>Use of patented medical information and conflict of interest in medical innovation</b>					X	X	X
<b>Reimbursement for genomic testing, interpretations and consultations</b>					X		X

# Where?



When? : September 2013