



newsletter

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PUBLIC POPULATION
PROJECT IN GENOMICS

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P³G EVENTS



Exuberance and talent? During the P³G celebration dinner, in keeping with tradition, many took to the stage and sang for their supper!

1 SAN DIEGO P³G GENERAL MEETING (OCTOBER 22-23, 2007). THE P³G GENERAL MEETING WAS EXTREMELY WELL ATTENDED; MORE THAN 90 DELEGATES FROM 20 COUNTRIES PARTICIPATED. This was in despite of the wildfires that raged across Southern California and uprooted half a million people.

Upon request from P³G members, the format of the working sessions was topic-driven. Twelve separate sessions discussing topics from MTA's to ontologies were held. Individuals were invited to attend sessions of their choice. Of particular interest, was the thought-provoking Genome Wide Association (GWA) data sharing presentation by Teri Manolio and Jan-Eric Litton. Please refer to the table on page 2 for a complete listing of sessions and outcomes.

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P³G E V E N T S

P³G hosted an exhibitor booth at the American Society of Human Genetics (San Diego, October 23-27, 2007). An estimated 250 individuals dropped by to seek more information. As part of P³G's fundamental mission of knowledge sharing and collaboration, Charter Members were offered space at the booth to place announcements, publicity and information.

2 YORK UK: INTERNATIONAL GENETIC EPIDEMIOLOGY SOCIETY (IGES) MEETING: A first version of the P³G *DataSHaPER*, formerly known as the Generic Dataset, was introduced during the IWG4 workshop in September 2007, following the IGES meeting in York. Ten experts participated in this working group to provide feedback on the finalization of the *DataSHaPER* and on long-term plans for future development.

DataSHaPER, an initiative spearheaded jointly by P³G and PHOEBE (Promoting Harmonization of Epidemiological Biobanks in Europe), is a set of questions on health outcomes, health determinants and physical and cognitive measures.

P³G San Diego General Meeting Sessions and Outcomes

Session	Outcome
Consent	Final information pamphlet and consent form to be integrated into the Observatory
Governance	Draft of generic approaches and models of governance
Access (to data and material)	Overview of Access Policies openly available to biobanks
IP / Ownership of biomaterial / MTA's	First draft of 'P ³ G Tool and Policy Guidance on Access To And Transfer Of Biobank Material' ready for comment
DNA quantity and quality control initiative	Two papers to be submitted
Open Ontologies	Results will be integrated into the Observatory
Open Biobank / Wiki for software	Website created providing access to tools, functional analysis started on some modules
Electronic biobanking manual	A new Observatory catalog is being developed
Generic Dataset (health outcomes, health determinants, physical and cognitive measures)	Structure revised, data collection ongoing
Assessing measurement of disease outcomes and intermediate phenotypes	Exploring collaboration with disease-oriented groups
Gene environment interactions: should we study them and what should we look for?	Discussion focused on long-term issues
Assessing biobank design, data structure and analysis (GeneStat)	Presentation of useful tools made available to the scientific community



Denis Legault, François L'Heureux, Paul Burton, and Isabel Fortier (left to right) at the P³G booth at ASHG, San Diego, October 2007.

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P³G E V E N T S

3 P³G BUILDING SYNERGY: SINCE THE LAST NEWSLETTER (SUMMER 2007), P³G HAS BEEN VISIBLE AT VARIOUS MEETINGS SHARING OUR VISION OF HARMONIZATION AND OF KNOWLEDGE TRANSLATION.

During the noteworthy events listed below, P³G participated in courses, workshops and presented our fundamental principles:

- Paris: INSERM, September 2007
- Manchester UK: *Biobanking: A Two-Day Intensive Course*, November 2007
- Paris: OECD workshop on the Global Biological Resource Sectors Centre Network - *Networking the Network*, December 2007
- Geneva: Brocher Foundation Symposium: *Translational medicine and public health policy: lessons from biobanks ELSI issues*, December 2007
- Atlanta GA: HuGENet workshop, January 2008
- Hinxton UK: BBMRI Kick-off and Stakeholder meeting, February 2008

THANK YOU TO GÉNOME QUÉBEC AND GENOME CANADA, FUNDERS OF THE P³G CONSORTIUM AND TO THE UNIVERSITÉ DE MONTRÉAL, OUR HOST INSTITUTION.

4 4TH ANNUAL P³G GENERAL MEETING WILL BE HELD AT THE BARCELONA PRINCESS HOTEL MAY 30-31, 2008

in Barcelona, Spain, two days before the European Human Genetics Conference. Multiple Topic Sessions will be held. Participants are welcome to attend any session and all P³G members are invited to take part in this exciting scientific event. (see table on page 4 for details). Registration can be completed online at www.p3gconsortium.org/Uevents.cfm.

The European Human Genetics Conference will be held at the Centre Convenicions Internacional in Barcelona, Spain May 31-June 03, 2008. For registration info, please visit www.eshg.org/eshg2008/

HEAR YE! HEAR YE! IWG3 MEMBERS, WHO ARE NOW RECOGNIZED AS THE MINSTRELS OF P³G, invite all IWGs to personally add their voices and talents to the vast repertoire of P³G during our Celebration dinner to be held on May 30 at 7 p.m.!!!



P³G ANNUAL MEETING SCHEDULE

BARCELONA, SPAIN, MAY 30-31, 2008
 BARCELONA PRINCESS HOTEL
 AVENUE DIAGONAL, 1

Friday May 30 7:30-8:30 a.m.	Breakfast
8:45 - 10:15 a.m.	Plenary Session One <ul style="list-style-type: none"> • Welcome Address • Observatory Update • Material Transfer Agreements
10:45 a.m. - 12:15 p.m.	Topic Session One <ul style="list-style-type: none"> • Governance • Problem Solving
12:15 - 1:15 p.m.	Lunch
1:15 - 2:45 p.m.	Topic Session Two <ul style="list-style-type: none"> • Guidelines • Genotype Storage
3:15 - 4:45 p.m.	Plenary Session Two (P ³ G/PHOEBE) <ul style="list-style-type: none"> • Future Vision for Population Genomics and Biobanking
5:00 - 6:30 p.m.	Poster Session
7 p.m.	Members' Dinner
Saturday May 31 7:30 - 8:30 a.m.	Breakfast
8:45 - 10:15 a.m.	Topic Session Three <ul style="list-style-type: none"> • DNA Quality Control • Access to Data/Material • DataSHaPER
10:45 a.m. - 1 p.m.	IWG Meetings (with lunch)
1:15 - 2:15 p.m.	Annual Members Meeting and IWG Reports
Sunday, June 01	
1:15 - 1:45 p.m.	ESHG Workshop

All members are invited to present posters describing the progress of their biobanks, or relevant issues or tools addressing these projects. If you plan on displaying your poster at ESHG, and the information meets these criteria, you may consider presenting it at P³G as well. All posters are welcome however, the preference is that they not exceed 2'10" (86.36 cm) wide x 3'8" (111.76 cm) high. The Poster Session will be held May 30, 5:00 to 6:30 p.m.

If you would like to display your poster, please confirm by email at dlegault@p3g.org under the subject heading: POSTER.

UPDATE FROM MEMBERS

CONGRATULATIONS to the following P³G Members on their recent Milestones

1 UK DNA BANKING NETWORK

(UDBN): The Network has recently received two years further funding from the MRC. Four of the eight disease collections within the UDBN were included in The Wellcome Trust Case Control Consortium landmark paper in genetic epidemiology.

2 THE CARTaGENE PROJECT:

Recruitment of the first Quebec (Canada) participants for the Optimization Phase of CARTaGENE started in January 2008. These individuals are chosen at random from the files of the *Régie de l'assurance-maladie du Québec* (Québec Health Insurance Board). The long-term goal of CARTaGENE is to collect environmental and health data from some 20,400 Quebecers.

3 LIFEGENE (SWEDEN):

has now obtained substantial funding through generous private donations. The short-term objective is to carry out a pilot study with 5,000 participants in 2009 and start recruiting participants for the main study in 2010.

4 NATIONAL BIOBANK OF FINLAND:

This facility currently houses DNA samples from over 200,000 individuals. Their aim is to deliver high-quality, quantity controlled DNA to researchers worldwide. During 2007, the National Biobank of Finland extracted close to 16,000 new DNA samples, and produced over 50,000 DNA aliquots and delivered quantified high-level DNA to numerous EU and NIH funded projects.

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UPDATE FROM MEMBERS**5 PHOEBE:**

Promoting the Harmonisation of Epidemiological Biobanks in Europe (PHOEBE) is run by the Norwegian Institute of Public Health and has 18 partners in 13 countries. The PHOEBE Second Annual Steering Committee Meeting will be held in Barcelona on May 28-29, 2008. PHOEBE and P³G will be holding a joint session at the Barcelona meeting on the “Future Vision for Population Genomics and Biobanking”.

6 THE NORWEGIAN MOTHER AND CHILD COHORT STUDY

(MoBa): This study will finish recruitment of pregnant women during 2008. By the end of the year more than 100,000 children in the cohort will be born, and the oldest ones will be turning eight years old. New questionnaires on the child’s somatic and mental health and also on the mother’s health are being developed and will be sent out when the children turn eight years.

Data analyses of questionnaire data have started, and over 20 scientific papers have been sent out and another 20 have been submitted.

7 NATIONAL INSTITUTE OF GENOMIC MEDICINE, MEXICO (INMEGEN): The Institute is currently conducting several population-based projects, some of them to describe the structure of the Mexican population, and others related to the identification of genetic basis of common disease.

Phase I has been completed; it includes genotyping and analysis of over 115,000 SNPs in 600 individuals from six remote areas in Mexico. Soon phase II will be finished, namely additional 550,000 SNPs in the same individuals. Recently, INMEGEN initiated genome-wide scan studies requiring sample collection of cases and controls with cardiovascular disease, obesity, type-2 diabetes, age-related macular degeneration, asthma, and other diseases.

INMEGEN has developed a detailed process for community engagement and individual consent to collect blood samples. In addition, sample collection in Amerindian populations has begun using similar strategies in their own local languages, respecting costumes and traditions in each community.

8 ONTARIO CANCER COHORT (OCC): In November 2007, the Ontario Cancer Cohort (OCC) submitted a proposal, in collaboration with other provincial cancer cohort leaders, to the Canadian Partnership Against Cancer (CPAC), to develop a Canadian Cancer Cohort. Funding in support of the national initiative was awarded in February 2008. Through this means, the OCC will receive funds for equipment purchase as well as salary support for database development and phlebotomy teams. The OCC remains committed to working with Ontario-based funders, including the Ontario Institute for Cancer Research, the Heart and Stroke Foundation of Ontario, and Cancer Care Ontario. The OCC study team is continuing to develop the detailed scientific proposal, which it expects to have completed by mid-summer 2008.

UPDATE FROM MEMBERS

NEW MEMBERS

The newest member to join the P³G as a Charter Member is the **National Guard Health Affairs (NGHA) Biobank** of King Saud Bin Abdulaziz University for Health Sciences (Riyadh, Saudi Arabia). Led by Dr. Mohammed Ali Al Jumah, this organization will provide community biobanking services for the Saudi nation, with a storage capacity of up to 200,000. Lifestyle, environment and gene interactions will be examined in a range of common late onset diseases.

Other new Charter Members include the National Cancer Institute (USA - www.cancer.gov), the NUGene Project (USA - www.nugene.org) and the Norwegian Institute of Public Health (Norway - www.fhi.no/eway/?pid=238),

The Alberta Cancer Board who is leading the Tomorrow Project (Canada - www.cancerboard.ab.ca), has recently joined as an Associate Member.

We are proud to have more than 30 Charter and Associate Members.

TELL US MORE. We would like to update our community on your successes and news. Please send suggestions to secretariat@p3g.org.

Charter Members

ALSPAC (UK)	National Heart, Lung and Blood Institute (USA)
CARTaGENE (Canada)	Norwegian Institute of Public Health (Norway)
Centre for Integrated Genomic Medical Research (UK)	NUGene Project (Northwestern University, USA)
Danubian Biobank Foundation (Germany)	Ontario Cohort Consortium (Canada)
Estonian Genome Project (Estonia)	Singapore Tissue Network (Singapore)
Generation Scotland (UK)	Taiwan Biobank Institute of Biomedical Sciences, Academia Sinica (Taiwan)
GenomEUtwin (Finland)	UK BioBank (UK)
INMEGEN (Mexico)	Western Australian Genome Health Project (Australia)
INSERM (France)	
KORA-gen (Germany)	
LifeGene (Sweden)	
LifeLines Cohort (Netherlands)	
National Cancer Institute (USA)	
National Guard Health Affairs Biobank (Saudi Arabia)	

Associate Members

Alberta Cancer Board (Canada)	German Center for Public Health Genomics (Germany)
Centers for Disease Control (Office of Genomics and Disease Prevention; Atlanta, USA)	Marshfield Clinic Research Foundation (USA)
Centre de Recherche en Droit Public (Canada)	McGill University and Genome Quebec Innovation Centre (Canada)
CIHR-Canadian Institute of Genetics (Canada)	Medical University of Graz (Austria)
European Collection of Cell Cultures (UK)	National Human Genome Research Institute (NIH, USA)
Genetics Resource Centre (Faroe Islands)	Ontario Institute for Cancer Research (Canada)
Genoma Espana (Spain)	Statistics Canada (Canada)
Genome Québec (Canada)	

A BOARD RESOLUTION was passed to facilitate the transition from Associate Member to Charter Member. For more information, please contact the P³G secretariat.

P³G OBSERVATORY

1 THE NEW VERSION OF THE OBSERVATORY WEBSITE WAS OFFICIALLY LAUNCHED AT THE P³G MEETING IN SAN DIEGO, displaying a fresh and ergonomic design and content aligned with IWG activities. Of particular note is the “What’s New” section, highlighting updates on the latest catalogues, software and repositories. Listed below are the most recent Observatory additions:

- *Physical and Cognitive Measures Catalogue*. This catalogue provides an overview of the measures collected by participant biobanks and when available, information regarding standard operating procedures. A comparison table of measures collected is provided as well. Observatory Catalogues provide easy and quick access to information about large population-based biobanks.
- *ESPRESSO Power Calculator*. ESPRESSO (Estimating Sample-size and Power in R by Exploring Simulated Study Outcomes) is a new R-based program for simulation-based power calculation that can be used to estimate realistic sample size requirements for case-control and cohort studies in population genomics. This software can be applied where analysis focuses either on direct genetic or environmental effects or interactions.
- As of mid-February, the Observatory listed 123 biobanks within the Study Catalogue and 20 questionnaires from 13 studies in the Questionnaires Catalogue.

2 TWO NEW OBSERVATORY CATALOGUES ARE BEING DEVELOPED:

- *DNA Processing and Storage Catalogue*. This catalogue will provide a snapshot of current practices of DNA processing and storing procedures.
- *Ethics and Governance Catalogue*. This catalogue will provide an overview of the ethical and governance strategies of participating studies.

3 GENERIC INFORMATION AND CONSENT FORM

WE ARE LISTENING. In response to your requests we have developed new Observatory section elements, including new tools and repositories. Thank you for your input. We are still in the process of evaluating some of these requests and look forward to receiving more.

www.p3gobservatory.org

I W G P R O G R E S S

TO DATE, NINE CORE PROJECTS OF THE INTERNATIONAL WORKING GROUPS (IWGs), the key independent research units of P³G have been formally identified. They are at various stages of development and are listed below.

Consortium members are encouraged to consider involving the P³G infrastructure in their proposed research projects. Advantages include, input from international leaders, rapid and easy dissemination of results, and formal technical and financial support from P³G for integration of tools into the Observatory. For more information or to apply, please visit www.p3gconsortium.org/cores.cfm.

P³G Core Projects

Core Name	Leader(s)	IWG	Deliverable
DNA Quantity and Quality Control	Martin Yuille, William Ollier, and H-Erich Wichmann	1	International guidelines for DNA measurements.
LipidomicNet	Gerd Schmitz	1	Guidelines for standardization of approaches in lipidomic science.
Obiba	Vincent Ferretti	2	Website, which includes an integrated suite of open source information management systems.
P ³ G Policymaking Core	Bartha Maria Knoppers	3	Series of papers on: consent/confidentiality and commercialization, data access and use policies, and governance models for population biobanks.
ESRC Innogen Centre	David Wield	3	To produce research advancing the social science knowledge base of the new life science economy.
Realistic Power Calculator for Population Genomics (ESPRESSO)	Paul Burton	4	Interactive tool including a list of variables to be used by and shared between emerging biobanks.
Reference Dataset	Isabel Fortier	4	Publications and software for comprehensive power and sample size calculation.
Development of Calibration Studies	Julian Little and Muin Khoury	4	Development of methods to calibrate measures of exposure used in different biobanks.
Assessment of Disease Outcomes and Intermediate Phenotypes	Julian Little, Muin Khoury, Paul Burton and Isabel Fortier	4	Identification of disease outcomes and intermediate phenotypes that will be comparable between biobanks.

GETTING TO KNOW



Kurt Zatloukal, avid skier, sailor, professor and coordinator of the BBMRI.

KURT ZATLOUKAL AND THE BBMRI PROJECT

Kurt Zatloukal is professor of pathology at the Medical University of Graz who specializes

in molecular pathology, focusing on metabolic and neoplastic diseases, mainly of the liver. He is a member of the Bioethics Commission at the Austrian Federal Chancellery, corresponding member of the Austrian Academy of Sciences, as well as, the Austrian representative in the OECD task force on biological resource centres. Moreover, he is a member of the P³G consortium steering committee.

Recently, Professor Zatloukal became the coordinator of the preparatory phase of a pan-European “Biobanking and Biomolecular Resources Research Infrastructure - BBMRI”, which will be funded by the European Framework Programme 7. This infrastructure aims at providing the technical, ethical, legal, and financial foundation to become a key resource in biomedical sciences, drug development and public health.

Below he shares his vision regarding this newly established organization.

Q: Can you describe the structure of the pan-European Biobanking and Biomolecular Research Resource Infrastructure (BBMRI)?

A: It is important to know, as a life sciences research infrastructure, the BBMRI is a first of its kind in Europe. Traditionally, research infrastructures have been developed for physical

sciences and as such, their roadmaps are different.

The BBMRI is a trans-national network with national and regional nodes enabling the movement of samples and data. These “hubs” are the basis of the structure and it is through these that activities are coordinated, including collection, exchange and analysis of samples and data for the major domains.

Q: What are the overriding goals of this organization?

A: The main goal of the organization is to provide access for the emerging needs of high quality biological materials and related technologies. In a joint effort we aim to coordinate, harmonize, standardize and integrate individual biomolecular resources into a pan-European research infrastructure that will render their combination much more powerful than each resource individually.

Q: Why is it necessary to establish such an infrastructure?

A: The answer is two-fold. It has been well established that access to high quality and sufficient quantity of biological material is a prerequisite for the advancement of biomedical research. Our goal is to facilitate this access.

There are many major European biobank initiatives all of which address similar issues, such as SOPs, ethical and legal frameworks, quality control, etc. To date, this has been done independently, resulting in similar but not necessarily, compatible solutions.

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P³G IN THE SPOTLIGHT

1 STAY TUNED FOR P³G

PUBLICATION POLICY NEWS. In an effort to strategically position P³G, the Board is considering endorsing a publication policy to clarify when contributions of P³G should be formally acknowledged in papers and presentations. This policy aims to support the fundamental P³G principles of transparency; openness, collaboration and knowledge transfer facilitation. This initiative will be discussed further at the Annual General Meeting in Barcelona.

2 CONGRATULATIONS TO P³G

BOARD MEMBER, GERALDO JIMENEZ SANCHEZ, who was recently elected as President of the Working Party on Biotechnology of the Organization for Economic Co-operation and Development (OECD). Geraldo Jimenez Sanchez is also General Director of the National Institute of Genomic Medicine of Mexico (INMEGEN). The tasks of this position are to chair working sessions of the member countries, concerning the definition and priorities on biotechnology at OECD.

3 CONGRATULATIONS TO P³G

BOARD MEMBER, LEENA PELTONEN who was appointed Head of Human Genetics at the Wellcome Trust Sanger Institute. Professor Peltonen is a member of the Finnish and United States National Academy of Sciences and is a world leader in genomic and genetic research. She pioneered the use of special population resources in candidate genes.

GETTING TO KNOW

This can be problematic when sharing resources. Our organization aims to coordinate and harmonize these initiatives.

Q: What is the benefit to organizations that make their samples accessible?

A: - Breakthroughs in genomics are critically dependant on the quality and quantity of the material which has been investigated. Therefore, those who provide this material will be recognized as a major contributor to the advancement of science. These groups will be the preferred partners for future research and projects, and may even qualify for public funding.

Q: Do you think your initiative will move beyond Europe?

A: Yes, because biomedical research is global. Any biobanking concept should be well embedded in such a context. We have already established fruitful contacts with other major organization's initiatives, which are global in scope.

Q: What type of collaboration do you see between P³G and the BBMRI?

A: I think we will have a very fruitful cooperation. The BBMRI will build on several aspects, which have already been elaborated by P³G. We neither want nor need to reinvent the wheel but can contribute to the completion of their work and add some new dimensions.