

# Advisory Committee on Genetic Privacy and Research

Meeting Minutes – May 6, 2009

**FINAL**

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## **Attendees:**

*Members:* Patricia Backlar, Kara Manning Drolet, Katrina Goddard, Stuart Kaplan, Steve Nemirow, Nan Newell, Gayle Woods

*DHS staff:* Bob Nystrom, Gwen Trieu

*Guest:* Susan Goldstein (PSU Faculty), John Silvey (PSU Student), Bonnie Russell (PSU Student).

## **March Agenda overview:**

1. Approval of March minutes
  2. PSU MBA Student Project – Final Report
  3. Direct to Consumer Genetic Testing talk and discussion – Amy Zlot
  4. Discussion of potential grant application RWJ Foundation for “PH Law”
  5. Other Business
  6. Adjourn
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### **1. March minutes approved**

### **2. PSU Student Project – Final Report**

- Interviewed 4 hospitals and 2 clinics
- Identities are coded on report
- All have different ways of doing the opt-out paperwork
- Expenses seem to increase for 2 hospitals in 2<sup>nd</sup> year

#### **Committee review and decision**

- Send report to committee members only
- Request identification and correction of errors in the findings from members representing the hospitals/clinics
- May need additional information to actually finalize this project
- Discussion of the report at the next meeting will lead to a decision on what to post on genetics website

### **3. PowerPoint Presentation by Amy Zlot, Oregon Genetics Program Epidemiologist “Direct to Consumer Genetic Testing”**

### **4. Potential Grant Application to RWJ Foundation for “PH Law”**

- Due dates
  - May 19, 2009 - Brief proposal due
  - July 13, 2009 - Applicants notified if invited to submit full proposals.
- Grant
  - Approximately \$3.5 million will be awarded for two types of research grants.

- *Short-term studies*: Up to 18-month awards of up to \$150,000 each.
- *Complex and comprehensive legal and public health studies*: Up to 30-month awards of up to \$400,000 each.
- Criteria
  - Significant public health problem and the impact of legal measures on health addressed.
  - The effective collaboration between public health and legal researchers and/or practitioners.
  - The potential impact of study results on the development, crafting and implementation of laws and policies that positively impact population health.
  - Translation to the practice community and policy-makers.
  - Ability of the study to advance methods in public health law research in general.
  - Adequacy of personnel and resources to complete the proposed project.
- ACGPR
  - Request support from all committee members
  - Request partnership with attorney who specializes in health care law

**5. Other business**

None

**6. Adjourn**