

**Advisory Committee on Genetic Privacy and Research**  
Meeting Minutes – June 4, 2008

**FINAL**

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**Attendees:**

*Members:* Patricia Backlar, Gwen Dayton, Erin Devaney (Rep. Galizio’s office), Kara Manning Drolet, Mark Loveless, Andrea Meyer, Steve Nemirow, Nan Newell, Gayle Woods

*Alternates:* Ted Falk, Stuart Kaplan, Ron Marcum, Terry Crandall (phone)

*Interested Parties:* Casey Bush, Kate Morris, Kerry Silvey (phone)

*Guest:* Bernie Andreotti (OHSU) (phone)

*DHS Staff:* Bob Nystrom, Gwen Trieu

**June Agenda overview:**

1. Announcements
  2. Input on Oregon Genetic Privacy Law (OGPL):  
Discussion with hospital administration/medical records representatives
    - Bernie Andreotti, OHSU
    - Casey Bush and Kate Morris, Legacy
  3. Passage of Genetic Information Nondiscrimination Act (GINA) and impact on OGPL  
Next steps for committee – Gwen Dayton and Ted Falk
  4. Adjourn
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**1. Call to order, introduction**

**2. Announcements**

**3. Input on OGPL regarding Opt-out Notice**

- Lab managers
  - No additional updates
  - Commercial labs are opting everyone out, independent of patient desires (and the law)
  - Commercial (non-hospital) clinical labs don’t use or sell samples for research
  - Do labels on specimens need to notify out of state labs of Oregon law?
  - **Action item:** Check back in with the lab managers in two years
- Hospital administrators and medical records
  - OHSU
    - Very few questions come up
    - Very few people are opting out
    - Opt out paperwork included in emergency patient package
    - If opt-out notice is mailed but is returned as undeliverable, system would default that patient as “opt out.” If mailed opt-out notice is not

returned or patient is contacted later, patient is presumed to have opted- in.

- Legacy
  - Sit down interview at 1<sup>st</sup> appointment
  - Documented in system for opt out
  - Is DNA extracted from cancer tumor patient covered by GINA?
  - The patient should only receive opt-out paperwork once

5. **OGPL updates:** Apparently some health care providers and pharmacies are not very aware or educated about OGPL.

- **Action item:** (unassigned) - Whose responsibility is it to distribute compliance information?
  - Licensing boards have limited information in regard to complying with law
  - What tools are available for distributing to and contacting health care professionals? (Licensing boards?)
  - HCPs need to help the community understand the law
- **Action item:** Gwen D. will ask OMA and Oregon Medical Board (formerly BME) about whether they would distribute compliance documents for OGPL
- **Action item:** (unassigned) Contact the Board of Pharmacy to see what they can to improve compliance.

6. **Passage of GINA and impact on Oregon Genetics Privacy Law:**

**Next steps for the committee:**

- Ted Falk distributed a collated copy of the OGPL with the 2007 revisions, a clean copy of GINA, and a document comparing GINA and OGPL in 5 areas:
  - Confidentiality
  - Definition
  - Purpose
  - Insurance
  - Employment
- **Action item:** All committee members will read the differences between GINA and OGPL
- **Action item:** Gwen T. will post these three documents to the State Public Health Genomics website
- **Action item:** Gwen D. will convene some members and other relevant attorneys to review the two laws and determine what issues need to be resolved.
- **Action item:** ACGPR will meet again when Gwen D. can lead a discussion on what issues need to be resolved. At that time, the committee will decide whether and how to proceed with proposed legislation in the 2009 session.
- Like OGPL, GINA does not distinguish between heritable and somatic mutations, which distinction is important to HCPs.

4. **Adjourn**