

**Advisory Committee on Genetic Privacy and Research**  
Meeting Minutes – March 3, 2010

**FINAL**

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**Attendees:**

*Members:* Patricia Backlar, Kara Manning Drolet, Anne Greer, Steve Nemirow, Nan Newell

*Alternate Members:* Ted Falk

*DHS staff:* Bob Nystrom, Gwen Trieu

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1. Review of agenda and approval of minutes for February 2010
2. Discussion of direct-to-consumer (DTC) genetic testing
  - Should committee consider taking action for Oregon?
  - The only states that have some regulation of DTC testing are:
    - New York: All laboratories must be certified by NY when testing New York residents.
    - California: All genetic test results have to be delivered by a California licensed physician or a genetic counselor.
  - Testing of Oregon residents falls under the Oregon Informed Consent, Retention, and Disclosure requirements. Thus, Oregon has appropriate laws for consumer protection.
  - A possible intern project would be to look at the major DTC genetic testing companies to see if their legal disclosure meets Oregon's legal requirements and if their medical disclosure/commentary reflects the current scientific literature (i.e., it doesn't over promise what the results will tell the consumer). The Genetics Program will consider this project for its MD medical geneticist who will be starting a rotation the 1<sup>st</sup> of April.
3. Review of agenda and approval of minutes for February 2010
4. RWJF Public Health Law grant – shall we resubmit?
  - Interest has been expressed by: Steve, Stuart, Marc, Anne, Shannon O'Fallon (DOJ), & PH administration
  - Application due April 14

- Needs more rewriting & references
- Marc has proposed Pacific Institute program for a similar (or same?) grant
- Nan will be the PI on this application

**5. Health Law section**

- Anne is still trying to get in touch with the section chair and hoping to talk to him next week.

Next scheduled meeting – TBA