

Advisory Committee on Genetic Privacy and Research

Meeting Minutes – July 1, 2009

FINAL

Attendees:

Members: Patricia Backlar, Kara Manning Drolet, Steve Nemirow, Nan Newell, Gayle Woods

DHS staff: Bob Nystrom, Gwen Trieu, Jessica Cass

Alternate: Ted Falk, Stuart Kaplan

Via phone: Gwen Dayton

Guest: Sharlei Hsu

July Agenda overview:

1. Review of agenda and approval of minutes for June 2009
 2. Discussion of analysis of GINA vs. OR genetic privacy law
 3. Other business
 4. Adjourn
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1. Brief introductions

2. Discussion of analysis of GINA vs OR genetic privacy law

- Gwen D.'s summary of the legal workgroup's initial conclusions on GINA and OGPL
 1. There are no preemption issues that directly contradict in GINA and OGPL.
 2. There are a number of differences, but they don't cause conflict.
 3. There are a number of nuanced differences that need analysis.
 4. OGPL has a big privacy component that GINA doesn't have.
- Discussion during meeting
 1. Need more detail and scope on **preemption issues**, more as a heads-up than any urgent effect on OGPL. We need to look at both types of preemption:
 - a. True preemption => Federal law makes Oregon law unenforceable
 - b. GINA gives us the Federal floor on genetic discrimination. If OGPL is lower, then it needs to be revised. If OGPL is higher, then it can be changed to match the Federal law or be left as it is.
 2. Does GINA present **policy** choices that we want to implement in Oregon?
 3. **Definitions** – There is a lot to be said for streamlining the definitions in the two laws. If we decide to make OGPL consistent with GINA, what are the effects?
- Project for OHSU legal intern: Sharlei Hsu
 - Sharlei only has a few weeks of internship. Thus, her work product will be reviewed and final changes discussed at the August meeting.
 - Work product for next meeting:
 1. Preemption analysis - Use Ted's GINA & OR law comparison as outline/template & highlight issues for further attention.
 2. Differences in definitions & what GINA definitions mean in the context of

OGPL (ripple effects).

3. Describe one or more scenarios for looking at the two laws and their implications

- **Draft ready for August meeting (8/5)**

3. Other business

- Oregon Genetics Program Intern (Jessica Cass) - Looking into licensing genetic counselors
- Trish got an email from John Silvey. He prefers to have participants remain anonymous.
- Trish also got a thank you letter from the PSU Business School Dean, and the School would welcome another project.
- Postpone approval of June meeting minutes due to not having minutes available.

4. Adjourn

Action items:

1. Trish to fax letter/emails from John & from the Dean to Gwen T. who will distribute to the Committee
2. Gwen T. to email all members June meeting minutes.
3. Invite members of legal workgroup to our August meeting (get names and emails from Gwen D. or Ted).
4. Draft from Sharlei Hsu on GINA & OR law analysis sent in advance of next meeting.

**Next ACGPR Meeting
August 5, 2009
Room 1C**

Tentative agenda items:

1. Sharlei's draft report – discussion
2. More conversation on DTC genetic testing
3. Update from Trish and Kara on PSU MBA costing study