

Advisory Committee on Genetic Privacy and Research
Meeting Minutes – September 3, 2008

FINAL

Attendees:

Members: Patricia Backlar, Gwen Dayton, Kara Manning Drolet, Mark Loveless, Steve Nemirow, Nan Newell, Gayle Woods, Marc Marengo

Alternates: Ted Falk, Stuart Kaplan, Ron Marcum,

Interested Parties: Kerry Silvey (phone)

September Agenda overview:

1. Genetic counselors' survey on impact of 2005 OGPL changes
 2. Discussion of Genetic Information Nondiscrimination Act (GINA) and impact on OGPL
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1. Call to order, introductions

2. Genetic counselors' survey on impact of 2005 OGPL changes

Survey conclusions:

- The survey was representative of Oregon genetic counselors (GC)
- The 2005 OGPL changes did not have an effect on GC practice because the “opt-out” issues were taken care of administratively before anyone saw a GC
- It was noted that all GCs in Oregon, except one, are associated with large medical centers, and that because Oregon does not have GC licensing, it can be hard to get reimbursed.

3. GINA and its impact on Oregon Genetics Privacy Law:

Gwen Dayton and Ted Falk reported on the first meeting of the GINA/OGPL legal review group, and led the ensuing discussion at the meeting. The initial conclusion is that the two laws have a “surprising number of differences” and proposing changes to the OGPL will not be simple.

- GINA only addresses discrimination in employment and health insurance, whereas OGPL also includes consent (for research). While the employment and insurance sections of OGPL are in separate chapters in ORS, the genetic definitions wind their way through all parts of OGPL, thus influencing the insurance and employment parts of OGPL.
- Definitions of genetic terms:
 - GINA is more expansive in its definitions, e.g., GINA uses “family members” whereas OGPL uses “blood relatives.”
 - Since OGPL and GINA use different definitions, we need to look very carefully and possibly separate out the consent part of OGPL from the employment and insurance part, especially if Oregon needs to use GINA definitions for employment and insurance (federal preemption).
 - The Committee needs to evaluate if GINA definitions are better than OGPL.

- What is the effect of GINA on HIPAA? The feds are tasked with looking into this.
- There are two components to the decision to propose changes to OGPL – legal and policy.
 - The first issue is legal: Does the federal law preempt Oregon law, and if so, specifically where? Are there parts of the Oregon genetic nondiscrimination law that is not affected by GINA? Are there parts of Oregon’s law that need changing or repealing? (Can we get a law student to do this research?)
 - When we get the answers to these questions, we need to decide what the outcomes will be if Oregon law is changed or repealed.
 - Then we need to present this information to the Legislature.
 - This process could take a year or more, especially since we don’t have any staff to work on it.
- During the summer, Joe Willis of Schawbe Williamson, who is working with a group that writes uniform laws for states, contacted Gayle who contacted Nan. This group has taken on GINA.
- Conclusions/decisions:
 - The Committee will not try to sort out the two laws and propose legislation for the 2009 session.
 - The Committee does not see any places where complying with one law would make it impossible to comply with the other law, but there are issues, and the analysis of the two laws should continue without delay.
 - Gwen D. will follow up with Joe Willis to see what is happening with a proposed uniform state law for GINA compliance.
 - Gwen D. will follow up with attorneys representing the Insurance Division and Bureau of Labor and Industry to see if they are working on integrating GINA into state law, including whether BOLI has a legislative proposal for the 2009 session. (The Insurance Division does not.)
 - As we move forward, we should invite representatives from the health insurance industry, large and small employers, and a union.
 - We will reconvene on one of our scheduled dates when more information from our partners and the legal review committee is available.

4. Adjourn