

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

FINAL

Attendees:

Members: Patricia Backlar, Kara Manning Drolet, Steve Nemirow, Nan Newell, Gayle Woods, Marc Marenco, Allison Naleway, Andrea Meyer, Marilyn Hartzell

Alternates: Ted Falk, Stuart Kaplan, Ron Marcum

DHS staff: Bob Nystrom, Gwen Trieu

December Agenda overview:

1. Approval of September minutes
 2. Announcements and updates
 3. 2008 Legislative Report Outline and Assignments
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1. September minutes moved to approval

2. Announcements and Updates

Gwen Dayton's updates

Per Gwen's email, nothing's happening since the Insurance Division has not yet completed the analysis to see whether or not they would work on integrating GINA into state law. It was asked whether Gwen had been in contact with Joe Willis as per the last meeting's discussion. She has not.

DHS staff updates

- Appointment has been done for Gwen Trieu as AS1 supporting Genetics Program
- Genomics grant award letter has been received and is effective November 29, 2008
- Nan is back to preparedness 10/15, and Bob is back from his leave as of 10/15
- Genetics Coordinator/OPA4 position hopes to open in 4-6 weeks

PSU Project

- Looking for MBA intern to analyze the hospital costs of the "Opt-Out" option
- If we are able to get an intern, it will be brought back to the committee for discussion on what additional topics he/she may consider in the analysis

3. Outline for ACGPR report to the 2009 Legislative Session (*assignments & deadlines*)

No meeting in January
1st draft due 1/7/09 - will circulate to all via email to gather input.
Complete draft for review at Feb. meeting (2/4/09)

1. Introduction (Kara)

- a. Include current state of things (GINA)
 - b. Mention work of Kathy Hudson's group/biobanks, Portland as community focus group site
2. **Recommendation for future activities** (Kara)
- a. Future activities, including examining GINA as described in #3, looking at costs of implementing opt-out (potential PSU project)
 - b. Advance a request for some funding to have resources available to the committee.
3. **GINA** (Ted and Gwen Dayton)
- a. Discuss work of sub-committee and other groups examining what effects GINA may have on OR law
 - b. Mention looking at definitions given challenges with current definitions
4. **1025 review** (Nan)
- a. Summarize work to gather input on current law/1025
5. **Genetic exceptionalism** (Trish)
- a. Mention work committee did to discuss

Appendices:

- Ted's report on GINA comparison
- Research/clinical/discrimination comparison charts
- Nan's summaries on input gathered from lab managers, researchers, hospital admin, genetic counselors
- Hudson's group analysis of GINA

4. **Adjourn**