

Advisory Committee on Genetic Privacy and Research
Meeting Minutes – February 4, 2009

FINAL

Attendees:

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

Alternates: Ted Falk, Ron Marcum

DHS staff: Bob Nystrom, Gwen Trieu

Guest: Susan Goldstein (PSU Faculty), John Silvey (PSU Student), Bonnie Russell (PSU Student).

February Agenda overview:

1. Approval of December minutes
 2. Genetics Team updates
 3. PSU Student Project
 4. Draft Legislative Report
 5. Committee Membership
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1. December minutes moved to approval

2. Genetics Team Updates

- Appointment request for Genetics Coordinator as OPA4

3. PSU Student Project

- 2 grads from PSU
 - Financial analysis specialize in finances & accounting
- Projected total time spend 150 hours per student
- Will conduct interviews with hospitals and clinics on the cost to implement and continue the “Opt-out” documentation; gather information using “Activity Based Cost Accounting Approach”
 - 1st phase: Costs to date
 - 2nd phase: forecasting tool if time allows
- Interns will need more contact information for hospitals and providers
- Request committee’s introductions to contacts prior to initiating project

4. Draft Legislative Report

- Genetic Exceptionalism
 - Trish to summarize and email to Nan by Monday 2/9
 - Options on Trish’s article
 - Very informative for individual’s understanding but private opinion and should not be in report
 - May reconsider for Appendix?

- Will discuss final draft at March meeting.

5. Committee Membership

- Membership renewal for 2009-2011 term
- Appointment letters to go out soon
- Kara and Trish have agreed to stay on as committee co-chairs

6. Adjourn