

Advisory Committee on Genetic Privacy and Research

Meeting Minutes – March 4, 2009

FINAL

Attendees:

Members: Patricia Backlar, Ron Marcom, Steve Nemirow, Nan Newell, Gayle Woods

Alternates: Ted Falk

DHS staff: Gwen Trieu

Guest: Bonnie Russell (PSU Student).

February Agenda overview:

1. Approval of February minutes
 2. Updates
 3. PSU Student Project
 4. Draft Legislative Report – final review
 5. Adjourn
-
-

1. February minutes moved to approval

2. Updates

- Nan mentioned that during the stem cell hearings at the legislature on 3/3/09, one testifier (from OHSU) said that the genetic privacy laws had had “unintended consequences” that she did not want to have happen with the stem cell bill. The Legislative Economic Development Committee members said they wanted to check into these unintended consequences.

3. PSU Student Project Updates

- Providence
 - Data done by end of week
 - Overview
 - The hospital & the clinics do not share records, so the opt out procedure had to be done in both places, which increased the administrative cost
- Legacy
 - Rec'd info from Casey
 - High rate of opt-out
 - Will compare data between Legacy and Providence
- OHSU
 - Will request meeting with Ron & all contacts
- Kaiser
 - To get together with Trish for contacts
- **FINAL PRESENTATION @ May Meeting**

4. Draft Legislative Report

All moved to accept legislative report with minor changes

5. Adjourn