

Advisory Committee on Genetic Privacy and Research Meeting Minutes — December 7, 2005

Attendees:

Emily Harris (co-chair), Gwen Dayton (co-chair) Gayle Woods, Jon Zonana, Michael Garland, Robert Nystrom, Andrea Meyer, Kara Manning, Kerry Silvey, Summer Street, and Naomi Adams

Welcome and Introductions

The committee reviewed draft minutes from the November 2, 2005 meeting. Emily Harris directed that the minutes were approved with the provision that they were still correctable.

Outcome:

Contact Naomi Adams at naomi.adams@state.or.us or call 971-673-0271 with further corrections to the November minutes.

Genetic Exceptionalism Presentation by Summer L. Street

The meeting opened with a discussion of the Genetic Exceptionalism research that Summer Street prepared.

The goal of her presentation was to provide a solid foundation for future discussion. Her discussion included an overview of the basis of the Oregon Genetic Privacy Act, policy concerns, what genetic exceptionalism means, as well as arguments for and against genetic exceptionalism. Summer will finish her report by the end of the month.

Please click on the icon below to view her full presentation in PowerPoint format



"ACGPR Presentation
Slides 12072005.ppt"

Other resources provided by Summer included a packet of materials for the Genetic Exceptionalism Presentation and a history of Oregon's Genetic Privacy Law **(Please click the icons below)**.



"ACGPR Presentation on Genetic Exception



"History of Oregon's Genetic Privacy Law.

The committee applauded summer for her excellent work on the project.

Outcome:

Summer will wrap up this project by the end of December. All research materials, including articles, the annotated bibliography and PowerPoint presentations can be obtained by contacting Naomi Adams at 971-673-0271 or naomi.adams@state.or.us.

Update on SB 1025 Timeline

Bob Nystrom discussed the progress of SB 1025. He explained that there was a very close timeline that needed to be adhered to. The final rules will be directed through the DHS rules coordinator for approvals.

At the hearing of November 30, 2005, there was some limited input. The ACGPR co-chairs read a statement and there was testimony from a Kaiser and an Oregon Medical Association (OMA) representative. Some technical issues were brought to the attention of the committee as well as some questions about newborn screening.

The most significant testimony came from the OMA. Their concerns centered around good faith in the law and the 14-day waiting period rule. They were concerned with the possible administrative impact this portion of the rule would have. For instance, there may be some difficulty recalling a sample that has already been forwarded if someone later objects to their sample being used for research. The OMA suggested a middle ground where the 14-day waiting period would not be required, but would be strongly encouraged or recommended.

Outcome:

Bob Nystrom will work with Shannon O’Fallon and Christina Hartman to finalize and submit SB 1025 by the end of the month.

Membership Update

Letters were sent to ACGPR members asking if they intended to stay on for the next two years. The goal is to have a tentative roster for the January 4,

2006 meeting. Michael Garland has not yet decided on the chair position. He is working to find a co-chair.

Outcome:

Naomi will bring a tentative roster to the January 4, 2006 meeting.

Educational materials

The Oregon Hospital Association would like to have some sort of brochures or educational materials to give patients so they can more easily understand the new rules. Gwen noted that the ACGPR would probably be the best group to create this sort of document, however, since the ACGPR does not have the power or resources to disseminate the information effectively she later agreed that the hospital association would probably take on the responsibility and post any finished product on their Web site.

Various formats were suggested including “question and answer” and something similar to the “notice and opt-out” form. The group acknowledged that the help of a health educator would be needed, noting that this would be a linguistic challenge. A health educator would be able to simplify the language in order to make it accessible to a wider audience. It was also suggested that a workshop for IRB’s be organized for the same purpose.

Outcome:

Gwen Dayton will work with committees at the Oregon Hospital Association to come up with some language for a brochure explaining the new rules.

Adjourned

Next Meeting January 4, 2006

1:00 p.m. to 3:00 p.m.

Oregon Medical Association

5210 S.W. Corbett Avenue in Portland