

**Advisory Committee on Genetic Privacy and Research  
Meeting Minutes — November 2, 2005**

**Attendees**

Emily Harris (co-chair), Marc Loveless, Mike Garland, Kara Manning, Bob Nystrom, Ted Falk, Andrea Meyer, Jon Zonana, Summer Street, and Naomi Adams

**Welcome and Introductions**

The committee reviewed draft minutes from the last meeting of October 5, 2005. After some minor corrections were noted, Emily Harris directed that the minutes of September 7, 2005 were approved with the provision that they were still correctable. Contact Naomi Adams at [naomi.adams@state.or.us](mailto:naomi.adams@state.or.us) or call 971-673-0271 with further corrections to the October minutes.

**SB 1025 Hearing**

The group discussed the upcoming hearing for SB 1025. It was suggested that co-chairs Emily Harris and Gwen Dayton prepare a statement about the rules to be read at the hearing. Andrea asked that the ACLU and other members of the committee be given the opportunity to read the statement beforehand. Emily said she would talk to Gwen and make a sincere effort to get something out.

Naomi Adams mailed the hearing notices to the interested parties. Naomi has also posted the hearing notice online at [www.oregongenetics.org](http://www.oregongenetics.org). Those who are interested in testifying will hopefully respond to the notice. A hearings officer will be present to administer the hearing and this person will report back the agency with any feedback, possibly including summary statement of the issues raised. The hearings officer will not have a substantive role in making any decision on the rules themselves.

The group also discussed the model consent form (Appendix 1) included in the packet. Members felt that the form is simply a model and this should be clarified. There is also a typo in the heading of Appendix 2 that needs to be fixed.

**Outcomes:**

- Emily will get together with Gwen to discuss a written statement about the rules to be read at the hearing.
- The noted typo will be fixed after the hearing before final submission.

### **ACGPR Membership**

The group then turned to a discussion of ACGPR membership. The current committee is approaching the end of the two-year term, which is January 2006. DHS appoints committee members except for those appointed by the legislature. Emily Harris and Gwen Dayton will be stepping down as co-chairs. The committee expressed interest in possibly having Michael Garland become one of two new co-chairs. Karen Jimenez has reappointed Senators Dennis Richardson and Gordon Anderson as member alternates.

Naomi Adams and Bob Nystrom will contact current members individually to see if they are interested in continuing as members or would like to step down. Kiley Arial and Kerry Silvey have been looking for other members who can participate regularly. There has been some difficulty in getting people to attend meetings on a regular basis. The committee hopes that new members will be able to attend and participate often, as their feedback is invaluable. Members suggested that Kara Manning, a regular participant who is a non-voting member, become a voting member, perhaps under Academic Institutions involved in Genetic Research.

#### Outcomes:

- Naomi and Bob will begin the process of contacting current ACGPR members to gauge their interest in continuing.
- Emily and possibly Gwen will talk to Mike Garland about the possibility of becoming a chair.

### **Genetic Exceptionalism Discussion**

Summer Street then updated the group on her research of Genetic Exceptionalism. Summer was asked to send presentation materials and handouts to the group via email as well as bring hardcopies to the committee. Summer will work with Naomi to forward electronic copies.

In examining the handouts Summer brought in, Andrea Meyer felt that some of the terms were not clear. She said she did not filter this information from a medical standpoint and asked for clearer language in the future. The group also expressed a desire to organize some of the information differently such as adding a column on testing on the basis family history. A pro and con table was also suggested as a helpful tool. The group was reminded that the legislature found 6 grounds for genetic exceptionalism and that all six needed to be covered.

Summer will be making a full presentation in December.

**Outcomes:**

- Summer will send the next set of documents electronically
- Summer will work on integrating the suggestions the group made for presentation of future materials including language clarity.

**Adjourned**

**Next Meeting December 7, 2005**

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

**Oregon Medical Association**

**5210 S.W. Corbett Avenue in Portland**