

Advisory Committee on Genetic Privacy and Research Meeting Minutes — January 4, 2006

Attendees:

Mike Garland (co-chair), Jon Zonana (co-chair), Kara Manning – Drolet, Senator Richard Devlin, Alissa Alexander (guest), Nanette Newell, Gayle Woods, Stuart Kaplan, Trish Backlar, Kiley Ariail, Emily Harris, Kerry Silvey, Bob Nystrom, Shannon O’Fallon, Robb Moses, Naomi Adams

Chair Election and Announcements:

Mike Garland and Jon Zonana were voted in as new co-chairs. The group then moved on to introductions and announcements. Kiley Ariail announced that she will be moving to South Korea. Bob Nystrom is working to reclassify Kiley’s so that the next person to fill her post will be a manager/team lead who will be able to grow in responsibility as the genetics program grows. Bob plans to open the position in about 2-3 weeks after he goes through the reclassification progress. Bob invited members to let him know if they are aware of anyone who might be a good fit for this position and is interested. Bob will email the formal job announcement to the committee. He hopes to have a replacement in place within two to three months once posted. The committee applauded Kiley for her hard work and dedication.

Outcome:

Bob Nystrom will work to have Kiley’s job posted as soon as possible and will pass the job announcement along to committee members as soon as it becomes available.

Re-appointments:

Allison Naleway will replace Emily Harris as the health care service contractor: genetic and health services research representative. Nan Newell will follow-up with someone in the bioscience industry. Bob will ask Mark if he has any suggestions for a pharmaceutical industry representative alternate. Kerry Silvey is working on the “Health care consumer” representative. It was also suggested that someone try and contact Carol Pratt because her contributions to the committee dialogue had been so invaluable. The final roster should be established prior to the February meeting.

Senator Devlin suggested talking with Katie King, DHS's legislative liaison about House Representatives who will sit on the committee this term. He also suggested getting House representatives who are geographically closer as this would make it easier for them to attend meetings. The two house representatives from the last term were both from Southern Oregon.

Outcomes:

- Committee members will continue to do their part to find replacements for those who have stepped down.
- Bob Nystrom will contact Katie King about possible House Representatives

SB 1025 Update:

The final rules were submitted. They will be posted on the www.oregongenetics.org website. One major change was the modification of the 14-day wait rule. There were also a few minor technical fixes. Some members of the committee were concerned that the model notification did not include a note to the patient on the 14-day rule. However it was later agreed that this piece of information could be built into the educational materials being developed.

Educational Materials:

The committee's intention was to tackle this as a first priority upon Kiley Ariail's return. However, since she will be leaving the program other committee members will take on this project. It was noted that there is no budget to print any materials, however the committee still sees this as a very high priority. The committee is considering a 1 page Q & A, Frequently Asked Questions page, or something similar. Gwen Dayton of the hospital association has agreed to help develop some language but DHS will really take the lead on this. It was suggested that the finished product can be posted on the DHS website where it would be available for download.

Genetic Exceptionalism

Michael Garland noted that the committee should deal with genetic exceptionalism for policy purposes as opposed to conceptual purposes and that the group should be sensitive to present historical context because of specific legal protections and obligations that need to be taken into consideration. He noted that this policy framework is distinct from a technical framework. He suggested structuring the problem in writing and

sending it out to committee members for comment. The purpose would be to carefully examine whether the committee wants to abandon genetic exceptionalism as a policy rationale or if genetic exceptionalism should be a part of the norm. He also suggested possible future breakout sessions on this issue.

Also discussed were the group's thoughts on whether or not there is likely to be a major legislative thrust in the area of genetic privacy. The committee agreed that there needs to be a "game plan" for dealing with issues that may come up such as different legislative options to take. SB99 was mentioned as an example where more planning may have been helpful and may have saved the bill. Senator Devlin suggested approaching legislatures from both sides of the aisle for support such as Laurie Monnes-Anderson.

Outcome:

Naomi will research the written/recorded testimony on SB99 in order to find out who testified and what the key concerns were.

Other Announcements

Trish Backlar announced an upcoming panel discussion called "Stigma Discrimination and Mental Illness". This will take place at Portland State University - there will be a panel on Thursday evening and a meeting with people to put together an anti- discrimination campaign.

Adjourned

Next Meeting February 1, 2006

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

Oregon Medical Association

5210 S.W. Corbett Avenue in Portland