

Advisory Committee on Genetic Privacy and Research

Meeting Minutes — February 4, 2004

Attendees

Astrid Newell (Co-Chairperson), Ted Falk (Co-Chairperson), Robb Moses, Nan Newell, Kara Manning, Kiley Ariail, Amy Zlot, Jon Zonana, Andrea Meyer, Carol Pratt, Kerry Silvey, Bob Koler, Emily Harris, Marc Marengo, Margaret Everett, Trish Backlar, Greg Fowler, Geri Washington, Laura Zukowski

Introduction

- Astrid Newell welcomed everyone. Two-year terms begin with this meeting. There are some new members and many returning members. All members should receive an appointment letter soon from Barry Kast, DHS Assistant Director. New members will receive some orientation in the future.
- Minutes from Last Meeting (November 5, 2003)
Outcome 1: Laura Zukowski will recirculate minutes of the November 5, 2003, meeting.
Outcome 2: Andrea Meyer moved to accept the minutes of the November 5 meeting with the provision that corrections may still be made. Bob Koler seconded the motion. The motion passed with no objections.
- Announcements/Updates
 - Marc Marengo announced that the National Institutes of Health has expressed interest in a grant application he wrote and has asked him to rewrite parts of it. If accepted, this grant would fund a two-year project about ethical and social implications of genetics within the context of faith communities, specifically within ten different religious denominations.
 - Kara Manning announced that OHSU and some other organizations are hosting a National IRB Conference in May. Organizers are looking for speakers to complete the agenda.
Outcome: Ted Falk volunteered to speak about Oregon's genetic privacy law.
 - Astrid Newell will speak next week to the Southwest Washington Medical Center's IRB about genetic privacy issues and ethical issues around umbilical cord stem cell research
 - Oregon Genetics Program staff has expanded to include: Amy Zlot, Genetic Epidemiologist, with a background in chronic disease and informatics; Kiley Ariail, Genetic Program Coordinator, with a background in public health and genetics.

Request: DHS staff will circulate some background documents to help orient new and returning members. These documents will include SB 618, the committee's charge, and a description of committee roles and responsibilities.

Committee Membership

DHS Assistant Director Barry Kast has given his verbal approval to the committee roster as it looks today. He is reviewing official appointment letters, so members and alternates should be receiving appointment letters in the near future.

There are still a few empty slots on the roster. Senator Peter Courtney will recommend a member and alternate for the legislative slots.

Outcome 1: Astrid Newell will send an e-mail to request feedback on appropriate divisions for 2004-2005 workgroups.

Outcome 2: A member moved to nominate Nan Newell and Gwen Dayton as co-chairs. After some discussion and indication by Nan Newell that she would prefer not to serve in this role, Andrea Meyer moved a friendly amendment to nominate Emily Harris and Gwen Dayton as co-chairs. Bob Koler seconded the motion. All members were in favor. None were opposed. None abstained. Emily Harris and Gwen Dayton will co-chair the 2004-2005 committee.

Outcome 3: DHS staff will ask Mellony Bernal to circulate a request among the DHS Health Services IRB to help recruit an alternate member for "Public Member of an IRB" slot.

Public Input — Education Subcommittee

Greg Fowler updated the committee on the public input survey. The Education Subcommittee currently consists of: Mike Garland, Chair; Greg Fowler; Astrid Newell; Kerry Silvey; Trish Backlar. In addition, Barry Anderson has worked on projects with this group as an interested party. The subcommittee continues to try to develop a survey that will be satisfactory to the committee as a whole. Greg hopes to present a final version at the March 3 meeting.

Outcome 1: The Education Subcommittee will circulate the next draft of the public input survey.

Outcome 2: As the committee's work progresses over the year, it may be beneficial to host some guest speakers on specific topics related to the work plan. Potential guest speakers would need to submit a written outline that would be reviewed in advance by the committee.

Suggestion: The Education Subcommittee may wish to consider hosting some special events or forums.

Meeting Schedule

The next meeting is scheduled for Wednesday, March 3, 1:00 to 4:00 p.m.

Outcome: *Laura Zukowski will send out an e-mail surveying members on their availability for future meetings. Meetings will need to continue to be three hours.*

Genetic Privacy Administrative Rules

Temporary administrative rules are in effect through April 16 or until permanent rules are filed, whichever comes first. There is a hearing on the proposed permanent rules on Tuesday, February 24. If there are not any major changes to the rules, they should be filed permanently in March before the temporary rules expire.

The Assistant Attorney General has responded to the DHS request to review whether a physician must obtain consent to retain genetic information in a medical record. The Attorney General's office has stated that DHS may not write an administrative rule that would exempt physicians from this requirement.

Insurance Administrative Rules

The Insurance Division is redrafting an authorization form for genetic testing in insurance underwriting. The Legislature charged the Insurance Division with this task. Jann Goodpaster has asked the committee for one to two volunteers to sit on a work group to rewrite the form.

Outcome 1: *Astrid Newell will circulate the draft insurance administrative rule and will send meeting information for the March 4 insurance meeting.*

Outcome 2: *Ted Falk volunteered to participate on the Insurance Division administrative rule around genetic testing.*

Outcome 3: *Emily Harris will invite Margo Neufeld to attend this Insurance Division meeting on March 4.*

Genetic Privacy Legislation

Astrid Newell announced that the Office of Family Health submitted a legislative concept for the 2005 session that would simplify the genetic privacy act and bring the statute more in line with HIPAA regulations:

- Exempt health care providers from the requirement to obtain signed authorization to retain genetic information in medical charts;
- Exempt health care providers from the requirement to obtain signed authorization for disclosure of genetic information during health care treatment, payment, or routine operations.

DHS Administration will review the two concepts, along with all the other concepts that various agencies submitted. DHS may or may not choose to propose one or both of these concepts during the 2005 session.

Outcome 1: Astrid Newell will send out an e-mail (before the meeting on March 3) that gives some background information about the two submitted legislative concepts and a description of which parts of the current statute would be affected.

Outcome 2: The committee will vote at the March 3 meeting on whether the committee wishes to endorse these legislative concepts.

Work Plan Issues

There was discussion about how to frame the work plan for the next biennium and how certain the list of eight issues developed. The issues reflect unfinished work from the past, assignments from the Legislature, and work that the committee assigned itself.

Outcome 1: Kiley Ariail and Astrid Newell will develop a summary document that describes of each of the eight work plan issues and will help guide discussion at the next meeting.

Outcome 2: These volunteers will write up a brief (single page) description of each work plan issue that gives some background information about each issue and what parts of the statute would be affected.

1 – state role in genetic patenting (Nan Newell)

2 – state role in regulation of genetic tests (Jon Zonana)

3 – use of genetic information by insurers (Ted Falk)

4 – informed consent (Astrid Newell and Trish Backlar)

5 – simplifying genetic privacy statutes (Bob Koler)

6 – protecting subjects of genetic research (Carol Pratt)

7 – definition of genetic information (Jon Zonana and Emily Harris)

8 – protections for individuals seeking genetic counseling (Margaret Everett)

Outcome 3: DHS staff will send a reminder e-mail to the committee and interested parties describing assignment and two-week deadline. DHS staff will summarize descriptions of work plan issues.

Future Meetings for 2004

Wednesday, March 3, 2004

1:00 to 4:00 p.m.

Oregon Medical Association

5210 SW Corbett Avenue in Portland

Future meetings beyond March will be scheduled at the March 3 meeting. Please bring your calendar.