

# Advisory Committee on Genetic Privacy and Research

## Work Session Minutes — March 5, 2003

### Attendees

Ted Falk (Co-Chairperson), Astrid Newell (Co-Chairperson), Emily Harris, Kerry Silvey, Jann Goodpaster, Bob Koler, Kara Manning, Greg Fowler, Patricia Backlar, Rowena Zirbel, Laura Zukowski

### Welcome/Introductions

Everyone introduced himself or herself. Jann Goodpaster, Consumer Protection Manager with the Oregon Insurance Division, attended as an alternate member from the Department of Consumer and Business Services. (Lori Long filled the position in the past, but has resigned.) Willamette University student Rowena Zirbel joined the meeting as a guest.

### Distribution of Legislative Report and Update on Web Posting

Ted Falk and Astrid Newell presented the committee's report to the Senate Judiciary Committee on February 25. The PowerPoint presentation was received enthusiastically even though the video clip from ELSI did not work. DHS Intergovernmental Liaison Katy King complimented the presentation. Due to the cost of printing the report, there is only one copy for each member and interested person. Additional copies may be printed from this website: <http://mchneighborhood.ichp.edu/pacnorgg/oregon/index.htm> . (This website is sponsored by the Maternal and Child Health Bureau of the federal agency Health Resources and Services Administration. It contains past minutes from this committee's meetings, along with many other documents related to genetics in Oregon.)

Astrid also reported that she has met with a DHS webmaster who has been redesigning the public health web pages. The website for the Office of Family Health will expand soon to include more information about Oregon's genetics program.

**Outcome 1: Astrid Newell will recirculate the MCHB genetics website address.**

### Legislative Issues

- ◆ Presentation to Legislative Subcommittee Update — As mentioned above, Astrid and Ted presented the committee's report to the Senate Judiciary Committee, which is chaired by Senator Minnis. The report lays the groundwork with the senators for the amendment (Senate Bill 618), which will have a separate hearing.
  
- ◆ Senate Bill 618 Discussion and Amendment — Senate Bill 618 has been printed. Everyone should have received a copy through the e-mail. Some changes were made to

the text that Ted submitted originally. In some cases, Ted believes the changes are improvements, especially in the definitions sections. All of the requested substantive changes seem to have been included, although a few sections seem unclear as of the start of this meeting, such as transition clauses and old specimens for which no consent is documented. Changes need to be made as soon as possible, so that Legislative Counsel can review them.

The group went through the bill page by page and discussed suggestions for changes. Below is a brief summary of agreements for edits.

Global Change: Use the term “anonymous genetic research” (in place of “anonymous research”) throughout the bill.

Page 1:

Line 8 — Insert the word genetic in front of the term “medical research.”

Line 11 — Expand the definition to end with the phrase, “. . . a DNA sample or genetic information used in the research is unidentified, deidentified, or not identifiable.”

Lines 26-30 — Delete completely.

Page 2:

Line 44 — Use “not identifiable” instead of “not identified.”

Page 4:

Line 27 — Insert the word “genetic,” so that (2)(a)(A) reads, “Has granted informed consent for the specific anonymous genetic research project.”

Page 6:

Line 29 — Delete “anonymous.”

Line 31 — Delete “appropriate” in front of the term “institutional review board.” An administrative rule could define the IRB as “appropriate” at a later date if there is disagreement about this deletion.

Page 7:

Lines 14-16 — Subsection 9 was discussed in terms of how it would affect study of historical samples that were collected before the 2003 law. Everyone present agreed that consent for use of new samples must comply with current law. No consensus was reached for wording of this section.

***Outcome 2: A separate work discussion will take place around this section, either face to face or through the e-mail.***

Line 35 — Insert the phrase “or individuals” after the word “Organizations.”

Also, there was a discussion about whether to expand membership to include representation from the insurance industry.

***Outcome 3: Membership will not be expanded to include an insurance industry category at this time. Representatives from the insurance industry will be included as consultants, on an as needed basis.***

***Outcome 4: Please contact Ted Falk as soon as possible if you have any requests for changes to SB 618.***

### **Insurance Issues**

◆ Insurance Division Rule for Genetic Testing and Life Insurance — Jann Goodpaster reported that the Insurance Division had received this committee’s letter commenting on the proposed administrative rules regarding genetic testing and life insurance underwriting. The division will be starting over in developing the rules and is planning to broaden their advisory group by adding a few representatives from this committee and some consumer members.

Future insurance-related issues to consider will include restrictions on underwriting based on genetic information, genetic patenting, and genetic testing. There was mention of what an insurance company may tell an individual who has been judged ineligible for underwriting or has had a policy cancelled based on genetic test results. The value of having some basic fact sheets about genetic testing that would explain in simple language privacy issues, risks, and benefits was mentioned, also.

***Outcome 5: ACGPR will identify a few representatives to serve on the Insurance Division’s new advisory board. Consumer representation is available through the ACGPR membership, also.***

***Outcome 6: The Insurance Division will keep in contact with the ACGPR as it develops the rules around genetic testing and life insurance underwriting.***

***Outcome 7: ACGPR will re-examine informed consent in parallel with the Insurance Division’s review of genetic testing in underwriting.***

### **Public Input/Outreach Subcommittee**

◆ Fred Friendly: Update and Next Steps — OHSU School of Nursing has turned down the opportunity to participate in Fred Friendly Seminar viewings/community meetings on their campuses. Current plans center around hosting pre-survey focus groups led by Michael Garland and Barry Anderson in three communities. Since OPB has a solid presence in terms of media contacts, etc., in the Bend, LaGrande, and Salem areas, the focus groups have been scheduled in those cities. There will be a focus group in both Bend and Salem during the week of May 12; a third focus group during the week of May 19 in LaGrande. At each session, the facilitators will show a segment of the first broadcast following a presentation. At least 8-12 people from each audience will participate in a focus group the following morning. Suggestions for the focus group discussion included the list of eight issues that have been identified and include future issues that ACGPR will address in the coming months. Discussion about the makeup of the audience for the evening included: tapping into a network of science teachers that a staffperson at OHSU has developed; inviting students, key persons at colleges and other institutions; inviting legislators and acknowledging how busy they are. The likelihood of

legislators showing up during a legislative session is not high, but some people felt that inviting legislators was important for keeping the door open for future communication.

◆ Survey Update and Next Steps — There has been some response to Barry's three questions that were circulated through the e-mail.

***Outcome 8: Greg Fowler or Barry Anderson will recirculate through the e-mail the three questions for the survey and request comment.***

### **Miscellaneous**

◆ Letter from a Concerned Father — A letter from a father who was asked to have his family participate in a genetic study has been circulating. In the letter, the father raises some concerns about privacy.

***Outcome 9: Astrid Newell will circulate the father's letter along with the twelve pages of replies.***

◆ National DNA Day — April 25 has been designated DNA Day by the federal government. There was a brief discussion about setting up a display table in the Capitol Rotunda on April 25.

***Outcome 10: Astrid Newell, Greg Fowler, and Rowena Zirbel will discuss this further and look into possible arrangements at the Capitol.***

### **Future Full Committee Meetings**

First Wednesdays —

May 7

July 2

September 3

October 1

November 5

December 3

1:00 to 4:00 p.m.

Oregon Medical Association

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