

# Advisory Committee on Genetic Privacy and Research Meeting Minutes—March 6, 2002

## Attendees

Astrid Newell, Ted Falk, Gwen Dayton, Andrea Meyer, Victor Leo, Mike Garland, Greg Fowler, Kathleen Walsh, Daniel Field, Patricia Backlar, Rachel Shapiro, Laura Zukowski

## I. Welcome/Introductions

Mike Garland announced that American Health Decisions and the Hastings Group are hosting an April conference in New York City on genetic literacy and public engagement around genetic policy and technological development.

## II. Old Business/Updates

- A. Update on Draft Administrative Rules**—Astrid Newell reported that the draft rules were submitted on February 8. They will appear in the Rules Bulletin on April 1. There will be one public hearing during the fourth week of April, to allow the public to comment on the rules. Astrid assumes the hearing will be in Salem.

*Outcome 1: Astrid Newell will circulate the February 8 redacted version of the draft rules through e-mail.*

*Outcome 2: May's agenda will include a section on testimony given during the public hearing.*

- B. Update on Gene Patenting "Seminar"**—Ted Falk sent an introductory letter to the Dean of the Northwestern School of Law to inquire if there would be any interest in having students participate in a seminar or project on gene patenting. He has received no response yet.

*Outcome 1: Ted will contact Willamette University School of Law or University of Oregon School of Law if Northwestern School of Law declines the invitation.*

*Outcome 2: Patricia Backlar will e-mail her colleagues at the National Bioethics Advisory Committee and ask for suggestions in locating an expert on gene patenting/intellectual property.*

*Outcome 3: Patricia will locate an article by Joan Tebo on this subject and share it with the group.*

### **C. Updates from Subcommittees**

1. Membership/Leadership—Astrid met with Kathy Walsh and Emily Harris to discuss their participation on the Clinical Issues and Research Issues Subcommittees. Kathy Walsh agreed to lead the Clinical Issues Subcommittee; Emily Harris will lead the Research Issues Subcommittee.
2. Activities—Each subcommittee has been assigned a topic area and will develop responses to the Legislature’s requests. The full committee will review this feedback and either accept, reject, or adapt the feedback. The final legislative report will summarize recommendations.
3. Timelines—Each subcommittee needs to have their feedback for the Legislature compiled by September, so that the full committee will have time to review feedback during September through November, and then write up the final report of recommendations during December. Subcommittee reports will need to analyze the reasoning behind all recommendations. There are approximately six months for subcommittees to discuss and develop their recommendations, which they will then submit to the full committee for review.
4. Education Subcommittee Update— Mike Garland reported that this subcommittee plans to have results of a public input survey compiled by September. Greg Fowler and Mike will be working on this today. They are going to set aside the education components temporarily and focus on this survey. A lot of activities around genetic literacy are happening currently around the country. Greg and Mike will be reviewing the information that comes out of these activities as the information becomes available. Marc Marengo is working on focus groups among religious minority communities in Portland right now, and this subcommittee is looking forward to those results. Rachel Shapiro, Community Genetics Planner with the Oregon Department of Human Services, added that she recently completed key informant interviews as

part of a larger public health genetics community assessment. A piece of this assessment included key informant interviews with leaders from various cultural, religious, and ethnic populations, in order to gather beliefs and attitudes regarding advances in the field of genetics.

*Outcome:* Rachel Shapiro is writing her report on results from the key informant interviews and will share this report with the committee when it is completed.

5. Neither the Clinical Issues Subcommittee nor the Research Issues Subcommittee has met yet. Some of these two subcommittees' work will be via e-mail, rather than through actual meetings.

### **III. New Business**

**Update on State Public Health Genetics Planning Project—**Astrid passed out an abstract of the Oregon Genetics Planning Project, which was funded by a grant from (the federal agency) HRSA that covers the time period June of 2000 through May of 2002. Among the goals of this project are the development of a statewide public health plan that addresses genetics issues across the lifespan, among different population groups, within the clinical care setting, and relating to public health data collection. The plan will cover more than just the future activities of the DHS Genetics Program, because it will address policy development, reimbursement, rural access, local community activities, ethical and social issues, etc. Work by state program staff has been guided by an internal steering committee that was broadened into an ethics and advisory council. Among the members of this council are genetics service providers, the OMAP director, consumers, and others.

Rachel Shapiro has been working on the assessment piece. Education of both the public and health care providers has emerged as a key issue in the needs assessment.

An intensive work plan summit is planned for April 4 in Portland.

*Outcome 1:* The Education Subcommittee is especially interested in the findings of the assessment. Astrid and Rachel agreed to bundle together relevant information and present it to the full committee. They will continue to update the committee on these activities.

Gwen Dayton and Ted Falk shared that they have been serving on a legislative task force that is working to integrate Oregon laws with the regulations under HIPAA (Health Insurance Portability and Accountability Act), which was revised under the Clinton Administration. The new regulations are scheduled to go into effect in approximately one year.

*Outcome 2: In response to a question about the differences between medical record privacy laws and genetic privacy laws, the Clinical Issues Subcommittee will review and report on this issue at a later date.*