

# Advisory Committee on Genetic Privacy and Research

## Meeting Minutes — July 7, 2004

### Attendees

Gwen Dayton (Co-Chairperson), Emily Harris (Co-Chairperson), Bob Koler, Kiley Ariail, Bob Nystrom, Kara Manning, Ron Marcum, Marc Marenco, Lisa Sardinia, Jon Zonana, Robb Moses, Andrea Meyer, Trish Backlar, Donaldda Dodson, Laura Zukowski

### Introduction

- Welcome and Introductions — Everyone introduced himself or herself.
- Review of Draft Minutes from Last Meeting (June 2, 2004)  
Draft minutes from June 2, 2004, had been circulated in the e-mail prior to this meeting. No one present had any requests for corrections or additions.  
***Outcome: Andrea Meyer moved that the draft minutes of June 2, 2004, be approved. Gwen Dayton seconded the motion. There were no objections. Minutes from June 2 were approved with the understanding that they may be corrected. Contact Laura Zukowski ([laura.a.zukowski@state.or.us](mailto:laura.a.zukowski@state.or.us)) if you would like to request any changes.***
- Trish Backlar brought two articles about subjects related to genetic privacy that she would like to share with the committee.  
***Outcome: Laura Zukowski will locate electronic copies of these articles (if possible) or will bring additional hard copies to the next meeting.***

### Genetic Privacy Protection in the Clinical Setting

Gwen Dayton brought another legislative draft to the group for review, which is less broad than the draft she presented last month. Today's draft would create carve outs in Oregon's genetic privacy law for health care providers, health insurers, and the state health plan for purposes of treatment, payment, and health care operations. The changes proposed in this draft would not affect discrimination provisions or the prohibitions against redisclosure and disclosure pursuant to subpoena.

Today's meeting is the last meeting before the July 15 deadline for the committee to decide whether it wishes to join the DHS legislative concept. If the committee decides to move forward with this draft, some amount of revision would still be possible as the draft moved through the various stages of the legislative process.

Discussion centered around technical questions regarding the purpose of the relating clause and potential for rolling together multiple bills and the legislative process itself. Multiple members expressed concern that the appointments to this committee for senate representation are not completed.

***Outcome 1:*** Emily Harris motioned that the committee should move forward with the version of Gwen Dayton's legislative draft that was reviewed by the committee today. Bob Koler seconded the motion. The motion passed with no opposition.

***Outcome 2:*** Members accepted Gwen Dayton's offer to work with Legislative Counsel in the future on developing definitions and creating other refinements to the legislative draft.

***Outcome 3:*** Gwen Dayton and Andrea Meyer will strategize on finalizing legislative appointees to this committee.

### **Research Work Group Report**

Emily Harris reported that the Research Work Group met on June 10 and began discussing current HIPAA protections for genetic information, and whether it would be desirable to maintain or increase protections under Oregon law. Work group members agreed that they need more time to consider legislative changes and have given themselves a deadline of January 1, 2005, to decide whether Oregon law should be changed and to draft any legislative language. In the next few months, the Research Work Group will continue to meet and study these issues. Future actions include considering the historical background of current Oregon law, comparing current HIPAA and Oregon protections for genetic information and biospecimens in the research setting, researching laws covering analogous tissues versus DNA specimens, and documenting barriers to research under current Oregon laws that govern genetic information.

***Outcome 1:*** If the committee decides to bring forward a legislative draft to amend the parts of Oregon's genetic privacy statutes that relate to researchers, it will be done separately from the changes proposed for clinicians.

***Outcome 2:*** Emily Harris and Kiley Ariail will work together to compile a list of various legislative approaches that other states have developed to protect genetic information.

### **Proposed Changes to Anti-Discrimination Language**

Jon Zonana presented draft language for revising ORS 746.135 and 659A.303 to broaden protections against discrimination based on genetic information of an individual or an individual's family members. He based his draft on language in President Clinton's Executive Order 13145 and (federal) Senate Bill 1053. This draft would expand the definition of a family member to include spouses and adopted children for these two statutes only (but would not change the definitions in the genetic privacy statute) and would expand the definition of genetic information to include family history and clinical diagnoses. The draft would expand protections against discrimination for seeking or receiving genetic services.

In his clinical practice, Jon reports that patients mention fear of discrimination in terms of employment, health insurance, and other insurance. The fear of discrimination comes up frequently in relation to genetic testing and genetic information, but fear of loss of privacy does not.

***Outcome 1:*** Jon Zonana will write a summary of how the anti-discrimination legislative draft would affect current Oregon law. The summary will include a description of why the committee is discussing the changes and will define the “problem” that the draft proposes to fix. This summary will circulate with the August agenda.

***Outcome 2:*** Emily Harris will contact Jann Goodpaster, who represents the Oregon Insurance Division on this committee, and will request her input on the legislative drafts that are under discussion.

***Outcome 3:*** The chairpersons and DHS staff will develop and send out the agenda for the August meeting earlier than usual. The e-mail message will urge recipients to read all attachments before the meeting, to send an alternate representative if they’re not able to attend, and to comment on the attachments if not able to attend.

### **Legislative Strategy and Timeline**

***Outcome:*** Bob Nystrom and/or Donald Dodson from DHS will talk to Katy King, DHS Intergovernmental Liaison, about inserting a placeholder into the draft DHS legislative concept. The committee has not yet decided whether to include the anti-discrimination piece in the draft, but inserting placeholder language will allow the committee to discuss the issue at the August 4 meeting.

### **Adjourn**

### **2004 Meeting Schedule**

August 4	November 3
September 1	December 1
October 6	

---

First Wednesday of each month  
1:00 to 3:00 p.m.  
Oregon Medical Association  
5210 S.W. Corbett Avenue in Portland