

Advisory Committee on Genetic Privacy & Research  
Meeting Minutes – June 7, 2006

**Attendees:**

Mike Garland (co-chair), Jon Zonana (co-chair), Nan Newell, Gale Woods, Stuart Kaplan, Ted Falk, Terry Crandall, Kara Manning-Drolet, Patricia Backlar

**Announcements & Introductions:**

No guests were in attendance. May meeting minutes were approved with no corrections. There were no major issues added to the proposed agenda, however Mike Garland announced that a discussion/decision on whether to have a July meeting would take place at the end of regular business.

**New Member Recruitment:**

New appointments to the ACGPR include:

Terry Crandall, Oregon Public Health Laboratory, formally agreed to be the alternate representative for the Oregon Department of Human Services (DHS).

Steve Nemirow, Kartini Clinic for Disordered Eating, will join the ACGPR as the representative for Public Members of Institutional Review Boards.

The only membership category without representation is Biosciences Industry. Several inquiries have been made by members but no interest has been generated. Kara and Nan indicate they would make additional outreach efforts. There is also not alternate to the Hospital member category. It was agreed that Gwen would be asked if she could help identify an additional interested member.

**Staffing Updates:**

The Genetics Coordinator (PC1) position was successfully offered and accepted with an effective hire date expected to be 7/6/06. A formal announcement will be distributed to members of the committee when the appointment is approved.

The Administrative Specialist (AS1) support position request to open is at DHS human resources and is expected to open within the next few weeks.

**IRB/Research OHSU Forum:**

Kara reported on the forum (April 28) and provided some additional reflection. She identified that the issues of 'defining genetic research' and what to protect are imbedded in the discussion of 'special status of genetic information' or 'genetic exceptionalism' and there is a need to complete this 'big picture' discussion to help guide issues/needs

related to working definitions. There was an acknowledgement that genetic testing is larger than the current 'definition' in statute. She suggested it would require an extended discussion to capture the complexity of the definitional work and it's implication/relationship to genetic privacy/research laws.

### **SB1025 Implementation:**

Casey Bush, Legacy Hospital Systems, provided some early feedback on SB1025 implementation/administrative burden. Their IRB suggested they would like to see an 'affirmative' opt-in process similar to HIPPA. He reported an estimated 20-30K in meeting time has been devoted to implementation and provided information on scope (# of annual notification anticipated) and concerns related to delayed hospital admissions due to patient education/signatures.

### **SB99 2007 Legislative Session:**

Ted Falk provided an overview of the history of genetic privacy law in Oregon and SB99. It was affirmed that the core concept of the original bill, improving HIPPA conformity and reducing barriers to information exchange related to healthcare treatment, payment and operations, was still valid. ACGPR members were still interested in advancing the legislative concept in 2007. It was agreed that a subcommittee comprised of Ted Falk and Gwen Dayton would draft a simplified SB99 concept for the August meeting as a starting point for ACGPR and that assistance from the Senate President Representative, Sen. Devlin, would be solicited to assist with a legislative sponsorship strategy.

### **Next Meeting:**

After a brief discussion, due primarily to calendar, staffing and member availability, a decision was made to cancel the July 5, 2006, ACGPR meeting. This would also allow in the interim, the SB99 subcommittee to meet and prepare the August draft SB99 concept.