

# **Advisory Committee on Genetic Privacy and Research Meeting Minutes — Dec. 6, 2006**

## **Attendees:**

Mary Pat Bland, Bob Nystrom, John Anderson, Steve Nemirow, Nan Newell, Jon Zonana, Mike Garland, Gayle Woods, Gwen Dayton, Stuart Kaplan, Ted Falk

## **December Agenda overview:**

- Agenda approval and approval of November 2006 minutes
- Introductions and announcements – upcoming events
- 2007 AGCPR Report to Legislative Assembly Draft
  - final review and adoption
  - plan for submitting the report
- Plan for legislative work on SB NN
- Continuing projects
  - Health Information Security and Privacy
  - Genetic Research Guide for Oregon IRBs
  - Discrimination education
- Nominations for Committee chair
- Adjourn

## **Outcome:**

- The November minutes were amended and accepted.

## **Introductions and Announcements**

There will be no meeting in January.

## **2007 ACGPR Report to Legislative Assembly Draft**

### **Executive summary:**

Include the fact that monitoring of SB 1025 will be discussed in document.

When discussing SBNN, include the fact that the increase in volume of genetic testing makes it especially important to be mindful of stringent but realistic privacy regulations.

Include bullet about public education about genetic discrimination and protections offered by Oregon and national legislation.

**Part 1 – Routine Disclosures of Genetic Information (Proposed Statute):**

- Doesn't explain existing HIPAA protections sufficiently
- Doesn't say enough about relieving burden on clinician
- Needs to speak to impact on health care workers and patient care

A comment was made that genetic information is defined narrowly, not broadly, the but implications are broad.

**Part 2- Patient Concerns About Discrimination- A Public Education Strategy:**

Move some language to the executive summary. The educational materials will be translated as necessary.

**Part 3:**

1<sup>st</sup> sentence and 2<sup>nd</sup> sentence of 1<sup>st</sup> paragraph in this section should be rearranged.

The suggestion was made to drop all four numbered points in this section or to incorporate the four points into a sentence or two.

b) please note that OAHHS and OMA were instrumental in notifying and supporting providers

d) include experience of researchers could say: "This law was intended to help researchers, but there is no evidence that it does or does not."

**Part 4:**

This should be condensed into part 3. Or, keep it separate and call it Educational Research Committee (with no mention of SB 1025).

**Part 5:**

Nonfinancial costs and benefits are not discussed. If part 5 (costs) lists the benefits, part 6 is not needed (access to health care). Section 7 (Scientific Developments) can be dropped, or needs more info.

Is the "need to get it right" important to emphasize, due to increased value or increased quantity of genetic technology?

**Outcome:**

- Nan Newell, Mary Pat Bland and Mike Garland are the final editing committee.
- Exact plan for submitting report is being determined.

### **Plan for Legislative Work on SB NN (Gwen Dayton)**

There is no bill number yet. Gwen is working on determining when bill will be coming out of legislative council. Senator Devlin will be introducing bill and the search for cosponsors is in progress. As soon as a date has been set for SB NN introduction/submission to judiciary committee, Gwen will let Committee know. It is crucial that other Committee members help Gwen share with legislators why SB NN is important. Providing legislators with background education information about the Genetic Privacy Act and existing discrimination protections will be key.

#### **Outcome:**

- Gwen will inform committee once a date has been set for SB NN introduction.

### **Continuing projects**

- Health Information Security and Privacy – Gwen Dayton  
Local group (<http://www.oregon.gov/DAS/OHPPR/HISPC.shtml>) received a funding to work on this national effort to address medical records interoperability. There was a specially protected records meeting on 12/7. The purpose of this local group is to contribute the national conversation about what to considered in this area. Gwen Dayton and Mike Garland are participating with this group; group is open to the public should anyone else be interested in participating. Gwen agreed to present a powerpoint presentation on issues related information to electronic medical records and creating solutions to the Committee during the Jan meeting.
- Genetic research Guide for Oregon IRBs – Mike Garland  
Mike Garland is getting a group together.
- Discrimination education – Jon Zonana and Mary Pat Bland  
We need to make sure the HIPAA section is correct. Also: lower reading level, don't use passive voice, and use a more common example for genetic testing (have one good example, not an exhaustive listing). Consider creating two versions of fact sheet- one for healthcare providers, another for consumers/the public.

#### **Outcome:**

- Gwen Dayton may present PowerPoint on Health Information Security and Privacy at the January meeting.
- Mike Garland is working on getting a group together for the IRB Genetic Research Guide.
- Mary Pat Bland will work on rewriting the genetic privacy educational materials and the assistance of public education subcommittee.

**Nominations for Committee chair** – Mike Garland

Mike Garland has decided to step down as Committee chair (possibly as early as January 2007). Interested members are encouraged to consider co-chair position. Committee is tremendously grateful to Mike for all of his work over the past years.

**Outcome:**

- Further discussion/nomination will occur in January.

**Adjourned**

**Next Meeting:**

**January 3, 2007**

**1:00 p.m. to 3:00 p.m.**

**Oregon Medical Association**

**5210 S.W. Corbett Avenue in Portland**

**Upcoming meetings:**

**February 7, 2007**

**1:00 p.m. to 3:00 p.m.**

**Oregon Medical Association**

**5210 S.W. Corbett Avenue in Portland**

**March 7, 2007**

**1:00 p.m. to 3:00 p.m.**

**Oregon Medical Association**

**5210 S.W. Corbett Avenue in Portland**