

# **Advisory Committee on Genetic Privacy and Research Meeting Minutes — March 1, 2006**

## **Attendees:**

Michael Garland (co-chair), Nan Newell, Ted Falk, Allison Naleway, Sen. Rich Devlin, Marc Morenco, Bob Nystrom, Kara Manning, Mark Loveless, Gayle Woods, and Naomi Adams

## **Welcome and Introductions:**

Everyone introduced himself or herself. Mike Garland encouraged everyone to go to the PSU forum on Direct to Consumer Advertising of Genetic Tests. He also referred the group to the DNA direct site, which he thinks is interesting. The site can be found at <http://www.dnadirect.com/>. The group was reminded about Patricia's public symposium on Stigma, Discrimination and Mental Illness.

Lastly, a public member of IRB is still needed. Patricia is going to look into calling Carol Pratt.

## **Outcome:**

**Co-Chair Michael Garland directed that the minutes of February 1, 2006 were approved with the provision that they were still correctable. Contact Naomi Adams ([naomi.adams@state.or.us](mailto:naomi.adams@state.or.us) or 971-673-0271) if you would like to request corrections to the February minutes.**

## **Genetic Coordinator Vacancy Update – Bob Nystrom**

Reclass for Kiley Ariail's position has been approved. Should get the draft recruitment announcement relatively shortly. It looks like as though the position will be posted within the next two weeks. As soon as it is open, Bob will send out an announcement. Members are encouraged to post to list serves and share with others who may be interested in the position.

The person will have some genetics education/knowledge and have some knowledge as to working in public health. This person should also be the team lead in management team. Bob will send the announcement and a revised position description to the ACGPR when ready.

## **Outcome:**

Bob Nystrom will email the position announcement to the group once it has been finalized. Members will be free at that time to post the position where they see fit as well as share the opening with prospective candidates.

### **Educational Materials - Bob Nystrom**

Bob thanked those who provided comments to the provider fact sheet. He told the group that Kerry Silvey has drafted the consumer fact sheet. He hoped to have a copy of the revised provider fact sheet, and a first draft of the consumer fact sheet prior to next meeting. He asked the group to reshare that one especially for input. The third and fourth versions of the fact sheet will be sent in a similar fashion and at the same time for comparison sake.

#### **Outcome:**

Bob and Kerry will work on the draft consumer piece. Once that is done, there will be an email sent out soliciting committee member comments.

### **IR B Forum Update by Kara Manning-Drolet**

OHSU would like to host another IRB forum. There will be a panel of discussion at the end and each panel will give a presentation in their area. Mike Garland will give an intro. Ron Marcum will also participate as he has expertise in HIPPA. Emily Harris will focus on what the changes are to the law. Gary Chiodo will talk about the new exceptions to research. Charlotte Shupert, IRB administrator from OHSU, will give some info on different case studies.

At the end there will be a Q&A from the audience. Researchers from both OHSU and Kaiser will be invited to attend. The forum is tentatively planned to take place on April 28<sup>th</sup>, 2006, which is a Friday, from 2 to 4:30.

Mike Garland noted that this would be a good time to unveil the IRB/Provider fact sheets.

#### **Outcome:**

Kara Manning-Drolet will continue to be the contact point for planning.

### **Genetic Exceptionalism discussion**

The conversation focused primarily on the reasons for the current laws and if they are really feasible. Members discussed the historical context, and how genetic privacy laws in Oregon grew up in a circumstance when there were no significant privacy statutes. Genetics did not seem problematic but genetics seemed particularly identifiable and a place to start to do something that is definable to protect consumers.

## **Reviving SB99**

The group then discussed the possibility of reviving SB99 and whether or not HIPAA sufficiently addressed the concerns that SB 99 would have.

The group acknowledged that the way the bill which had been presented may have been problematic, particularly the anti-discrimination piece. There was not at that time, nor presently a consensus on what the group wanted to do with the Bill however most agreed that reviving the bill with changes should be considered. Bob Nystrom explained to the group that though this is still an important issue, DHS has taken this Bill off the list of legislative priorities. However, he did say that he would check with Katy King to see if there was a possibility that DHS would again sponsor the Bill although he seemed to think this was not a very strong possibility.

Senator Devlin discussed some ways to bring a Bill to the legislature more effectively during the next session.

### **Outcome:**

- Bob Nystorm will check with Katie King about the possibility of DHS sponsoring a revised SB99
- Naomi will make sure the group gets a copy of SB 99 before the next meeting.

## **Adjourned**

**Next Meeting April 5, 2006**

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

**Oregon Medical Association**

5210 S.W. Corbett Avenue in Portland