

**Advisory Committee on Genetic Privacy and Research  
Meeting Minutes — April 5, 2006**

**Attendees:**

Mike Garland (co-chair), Jon Zonana (co-chair), Gayle Woods, Nan Newell, Kara Manning, Kerry Silvey, Mark Loveless, Andrea Meyer, Patricia Backlar, David Holt, and Naomi Adams.

**Welcome and Introductions**

**Michael Garland –**

The Citizens Workgroup on Healthcare is going to host one of its meetings in Eugene on the 18<sup>th</sup> of April from 10 am to 2 pm. These meeting are organized by a public forum group from New York. Mike will have Naomi send the full information around to the committee. They will make recommendations about a healthcare program that works for all Americans. There is bipartisan support for this.

**Approval of Minutes::**

**Co-Chair Mike Garland directed that the minutes of March 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 changes to the March minutes.**

**Genetic Coordinator Hiring – Kerry Silvey**

The position has been posted and will remain open until 4/13/06. The job posting will remain posted for 3 weeks. If no one is found during the initial posting the opening will be relisted.

**Outcome:**

Bob or Kerry will keep the group posted on any new developments.

**Bioscience Industry Representative – Nan Newell**

Nan Newell is having some difficult locating a bioscience industry representative. She suggested leaving this spot open until interest arises in the industry.

The search continues for a member who is aPublic member of an IRB. The person in this position should be someone who is not connected with research industry

Kerry has a lead on a public member who was not going to be available until July. She will contact her.

**Outcome:**

Kerry Silvey will contact the potential Public IRB rep. And report back to the group when she hears something. Further efforts will be made to recruit a participant from the Bio-science Industry.

**Patricia Backlar on Stigma Public Symposium**

The Stigma Symposium will happen April 27, 2006. The symposium is a kick off to the actual hard work Patricia Backlar and her program at PSU will be working on for the next year or possibly longer. Richard Warner, PhD will be the keynote speaker who helped direct the global campaign for the World Psychiatrist Association Programme to reduce Stigma and discrimination because of mental illness.

**The Education Materials Update: The Healthcare Provider Fact Sheet. – Kerry Silvey**

Everyone's ideas have been incorporated. It now needs to be formatted. There will be two formats, a PDF format to be posted to the web with DHS logo as well as a word version that can be adapted that does not have the DHS logo.

For the consumer fact sheet – Kerry asked the group if they wanted this sort of fact sheet to be shorter and simpler or more complete which would make it more difficult to read and more complex. Mike Garland thinks it might be good to go with a dialog format. The provider sheet is good, but the consumer version needs to be simpler and more direct (6 grade reading level).

Bob and Kerry will work on it some more. Andrea and Mike Garland say that all four don't need to be similar. IRB and researcher will be very similar, the other two will not. Emily Harris has made a PowerPoint of what she feels are the key issues for the IRB FAQ. This will be addressed during the IRB forum scheduled for April 28.

**Outcome:**

- Naomi will work on formatting the FAQ's once complete.
- The final Consumer FAQ will go out to members for final approval.

### **The IRB Forum - Kara Manning-Drolet:**

The flier for the IRB Forum has gone out. Please invite people. Registration is suggested. DHS has a list of all the IRB's in Oregon. The IRB Forum has been posted on the IRB list serve. There will be a report on this at the May meeting.

### **Genetic Exceptionalism Discussion**

The group continued their discussion on framing the ACGPR's Inquiry into the rationale for special laws regarding the privacy of genetic information.

#### **Context:**

Oregon's genetic privacy statutes were created in the pre-HIPAA environment. Rather than take on the much more daunting task of creating a privacy statute to apply to all medical records, the original legislative effort selected genetics as a definable area of medical records and privacy. The genetic exceptionalism basis for Oregon's genetic privacy statutes does not come from a belief that genetics raised unique privacy problems, but that genetics was a manageable subset of privacy issues related to medical records and the collection and storage of diagnostic tissue.

#### **Question:**

Given the implementation of HIPAA regulations, is there any need for Oregon's genetic-specific privacy statute and subsequent regulations?

#### **Sub-questions:**

- What specific elements in the Oregon genetic privacy statute and regulations are not included in the HIPAA regulations? (We need to list them.)
- Do any of these elements justify the continued existence of Oregon's genetic privacy statute and regulations? (We need to identify them.)
- What are the legislative consequences of these answers?

The group discussed the impact of HIPAA and the current state of Federal Genetic Privacy legislation

### **Jon Zonana – Genetic Discrimination**

Jon referred to the SCGAS website as an excellent site saying that they have gone out of their way to educate as to the public's concerns (educating legislators and public servants). The URL is <http://www4.od.nih.gov/oba/sacghs.htm>.

Oregon legislation is very good in terms of the prohibition of being tested if you are presymptomatic and having that used against you. This is similar to the proposed federal legislation.

Kerry Silvey told the group that Sharon Terry, President & CEO Genetic Alliance is working on getting additional Republican and Democratic sponsors for the Federal Legislation. They are trying to keep it balanced. Apparently the work they have been doing has been with health lobbyists, health insurance groups, big business and small business lobbyists. Lobbyists for health insurance companies have said they are not going to oppose it because it will probably affect others equally. A sticking point in both the Federal Legislation as well as what had been proposed for Oregon legislation in SB 99 was the proposed family history clause. Kerry suggested that it would be beneficial to have an outside analysis of the Oregon Statute in order to help resolve this issue before moving forward. Jon Zonana felt that the issues covered by SB 99 really are a national issue that require a national solution and would therefore be better served at the Federal level with Federal legislation. He recommended that ACGPR not seek to create a new SB 99 Bill.

### **Adjourned**

**Next Meeting May 3, 2006**

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

**Oregon Medical Association**

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