

Advisory Committee on Genetic Privacy and Research

Meeting Minutes — April 6, 2005

Attendees: Emily Harris (co-chair), Gwen Dayton (co-chair), Bob Koler, Michael Garland, Patricia Backlar, Stuart Kaplan, Kara Manning, Mark Loveless, Mike Becker, Kiley Ariail, Naomi Adams

Welcome and introductions:

Dr. Mark Loveless of Roche Laboratories joined the committee as a representative of the pharmaceutical industry. Mark Loveless, PHD works in the infectious disease, HIV and Hepatitis C group of Roche Medical Labs. He was the state AIDS director and has done a lot of work in public health, as well as some in private practice. Everyone then introduced himself or herself.

Outcome: Co-Chair Emily Harris directed that the minutes of March 2, 2005 were approved with the provision that they were still correctable. Contact Naomi Adams (naomi.adams@state.or.us or 503-731-4021 xt: 537) if you would like to request changes to the March minutes.

Senate Bill 99

A hearing for Senate Bill 99 was held on March 29, 2005 in front of the Senate Judiciary Committee. The bill was heavily criticized by the legislators who were concerned about the use of genetic information in insurance underwriting. They were also concerned that the anti-discrimination portion would not be strong enough. Gwen said she was left with the impression that there was a lack of understating of fundamental issues that brought the bill to the legislature. This misunderstanding has not been cleared up. She felt that the Committee's primary concern is the lessening of privacy and protection against any use of personal genetic information.

Gwen and Betsy Earles of Kaiser made an appointment with Senator Burdick. However Senator Burdick canceled the meeting at the last minute. Senator Burdick had expressed the most concern over the insurance portion of the Bill. Senator Prozanski was also concerned that the Committee would remove protections established in 1995. While in Salem Gwen spoke briefly with Senator Burdick. Sen. Burdick expressed concern about the insurance part but was unable to talk for very long. Gwen feels the Bill will probably proceed with either the insurance part taken out or with the health care operations part saying that insurance underwriting is not included. Gwen also feels Sen. Burdick will listen to this issue again in a modified form.

Emily pointed out that the legislators had expressed an interest in hearing from consumer advocates and that someone contacts Margaret Everett and others who could testify on the bills behalf.

Gwen asked the group if they thought the insurance portion of the bill should be removed and then just proceed with the provider portion. She added that consideration had to be given to whether taking out the insurance portion of the bill would hurt Kaiser who was there supporting the bill.

Mike Garland suggested amending in something that says the insurance portion of SB99 has absolutely nothing to do with underwriting.

Because the concepts in the Bill have been explained but not understood by the Committee, Trish suggested writing a primer of basic information about the legalese and medicalese with simpler language.

Mike Becker also suggested making a timeline of how we've dealt with genetic issues. For instance, Oregon implemented genetic privacy protection in 95. Since then, HIPPA has become effective. Now we are in a position where there is some disparity in the way we are treating providers and insurers. Legislators should understand why the group has made the recommendations that it has.

Stuart Kaplan noted that recently Andrea Meyer had some concerns about the Bill in its current version. He thinks she is less concerned now but noted that she also observed what happened at the hearing. Stuart doesn't feel there is any strong ACLU opposition to Senate Bill 99. However, he conceded that the ACLU generally only comes out in support of a bill when it significantly extends privacy rights. He did not believe the ACLU would "go out on a limb" with support of this particular bill.

Gwen told the group that the anti-discrimination provisions were holding up the bill. Ultimately she planned to get an appointment with Senator Burdick and wants to amend the anti-discrimination portion of the bill very quickly. She suggested that if for some reason SB 99 can't be used as a vehicle to introduce the anti-discrimination proposal, then the group would have to be quick about finding another way of introducing the proposal.

Mike Becker is concerned that amending the anti-discrimination provision could cause other issues – that amending it may bring in more opponents to the bill that were not anticipated.

Gwen pointed out that the anti-discrimination provision has to be someplace if not in SB 99. One option is to get legislators to use a priority bill. Since our Legislative representatives have not been active or responsive we may have to find some one else, or perhaps find another bill that's already had a hearing that will fit the anti-discrimination piece. She agreed that we might raise the ire of some people.

Associated Oregon Industries or AOI and other businesses might oppose it. The next step is Gwen will try and get in and talk to both Burdick and Pozanski.

Outcomes:

- Gwen will make an appointment to meet with Senators Burdick and Pozanski and will get back to the group once this happens.
- Emily will contact Margaret Everett and Kiley will identify and contact others who could potentially testify on behalf of the bill.
- The anti-discrimination proposal will be provided to the Judiciary Committee as requested. The Committee may consider amending the piece in to SB99.
- Kiley will send out the revised version of the proposed language.

Senate Bill 1025

Gwen - OHSU was the entity that got this bill introduced. She spoke to Brian Boehringer and he is gathering people from OHSU who are interested in testifying in support of the bill. Gwen thinks even more concern may be raised with this bill than with SB99. Brian is aware of concern and is getting people to come in and talk about what -the bill means to researchers.

SB1025 has been assigned to the Committee on Rules. It may then be sent to the Judiciary Committee. Rules is a catchall committee. Sometimes they refer bills out to a more appropriate committee. This bill will have a hearing fairly soon, perhaps in a week or two.

Kiley Ariail pointed out that some consumers might need coaching and education by the committee before the hearing.

Kara Manning said that Gary Chiodo might be interested in testifying.

Kiley Ariail noted that the idea of asking Paul Newton to testify had come up because he represents consumers and IRBs (specifically, public members of IRBs). Kara Manning said that Jon Zonana might know some patient groups and Kiley said she would follow up with him. Trish Backlar also volunteered to testify.

Mike Becker felt that a one page outline of the protections that are would be protected or strengthened by this legislation should be created.

Stuart agreed with Mike Garland's idea that the group should show how this bill increases privacy or makes existing laws work well instead of simply relying on testimony from consumers.

Emily said we could request to present the report at same time as SB99 or present in a totally different setting. Presenting it at the same time at SB99 is good, but given the

trouble we had on SB99 we want them to focus on SB99 and not the report. Also if they don't like the report they may vote down SB99.

Kiley asked Gwen about the likelihood of getting another opportunity to present the report. Gwen said it was likely but time is of the essence.

Gwen will ask Senator Burdick if she'd like the committee to hear the report and how she would like it presented.

Emily will revise the research section relating to recommendation 4 to remove the "balance" wording and replace it with wording that emphasizes the overall strengthening of research regulations.

Outcome:

Gwen will ask Senator Burdick if she'd like the committee to hear the report and how she would like it presented.

Emily will make the proposed changes to the legislative report as decided by the group. The revision will be sent out for review and comment with a very short turn around deadline.

Other Business

Discussed Trish Backlar's symposium, which went very well. The symposium called Genetic Testing, Privacy, and Race was held at Portland State University. The purpose of the symposium was to discuss policy issues and the potential for misuse of genetic information. Over 200 people were in attendance. Some of the guest speakers included members from the ACGPR Committee including Marc Morenco and Jon Zonana.

Kiley Ariail is seeking volunteers to participate in a panel discussion at the Oregon Genetics Programs upcoming Symposium to be presented to the combined Oregon MPH program.

Adjourn