

Advisory Committee on Genetic Privacy and Research Meeting Minutes — May 3, 2006

Attendees:

Mike Garland (co-chair), Robert Nystrom, Greg Fowler, Allison Naleway, Nan Newell, Gayle Woods, Gwen Dayton, Kara Manning-Drolet, Stuart Kaplin, Patricia Backlar, Tyler Johnson (guest), Verne Steverson (guest), and Naomi Adams.

Announcements and introductions:

There were two guests present from PSU from Greg Fowler's class. They came to report on the direct-to-consumer genetic testing forum hosted by fellow PSU students in Greg Fowlers class.

Members of the committee disagreed with a statement as written in the previous minutes. The statement asserted that the origin of Oregon's genetic privacy laws did not arise from a belief that genetic information deserved special privacy protections. Mike Garland asked that this sentence be changed to more accurately reflect what was said. The minutes were then approved as corrected.

Outcome:

Co-Chair Michael Garland directed that the minutes of April 5, 2006 were approved with corrections and with the provision that they were still correctable. Contact Lisa Estes-Vanlue at 971-673-0249 if you would like to request further corrections to the April minutes.

Genetics Coordinator Position and Naomi's Resignation – Bob Nystrom

The Genetics Coordinator position has closed. There were 8 qualified candidates. Out of those, five were interviewed. Two finalists were identified. Bob Nystrom hopes to have finalist's interviews completed by the middle of April and the name of the person filling the position by July although the actual start date will depend on the candidate and their needs.

Naomi Adams, the current administrative assistant for the Genetics program and also the minute taker for the ACGPR meetings has announced her resignation. She will be pursuing other interests as a law student. A requisition for her replacement has been submitted to DHS Human Resources. The Committee members expressed their gratitude to Naomi for her excellent work on behalf of the Committee.

Outcome:

Bob will keep the committee posted as things develop in this area.

ACGPR Membership Update

State Representatives Vicki Berger and Kevin Cameron have been officially appointed to the ACGPR by the Speaker of the House of Representatives..

Also a candidate for the position of the public member of an IRB has expressed interest in serving on ACGPR and will give a decision by the middle of April.

Terry Crandall, county health department labs liaison, has said he would be open to becoming part of the committee as the alternate for DHS replacing Cheryl Hermeroth who previously had been the alternate for DHS. He has agreed to talk to Bob Nystrom further about the position. Nan Newell will also talk to him since she is the current primary DHS rep.

Outcome:

Naomi will verify membership status for the two prospective members prior to the next meeting and send welcome letters to them once they officially accept.

PSU update – Direct to Consumer Testing Public Forum - Greg Fowler

Two of Greg Fowler's students came to report on the direct-to-consumer testing forum their class hosted earlier in the month.

Tyler Johnson reported that the forum had a diverse attendance. There were many different people from the Portland community including some medical professionals. There will be a report on the Geneforum website.

Some of the issues he heard expressed were hopes that this new science might be helpful to future generations and the ease with which this testing might become available to the general public because it can be obtained via the internet. The concept of genetic exceptionalism was spoken of a great deal. Many hoped this would benefit future science and research.

However there were concerns as well. The most prevalent seemed to center around discrimination. There was also concern that there may be a high probability of misinterpreting the information. For instance, lay people may be more prone to misread or not understand the information. Also, there may be a gap in "classes" of people who can afford these tests and those who cannot.

Tyler noted that there also seemed to be some confusion over things such as why there is a difference between tests ordered over the Internet and those administered in a doctor's office.

Verne Steverson actually ordered a genetic test from an internet vendor to give his fellow classmates and himself a better understanding of what the process entails. He explained to the group why he decided to take the test and the process he had to go through to take the test. He tested for Hemochromatosis as he has a family history of it. The story he

related to the group about his experience was riveting. Members of the committee were impressed and expressed interest in seeing his story put into writing.

Greg Fowler noted that Internet companies range from the reputable to reprehensible. DNA direct is one of the more reputable ones. He and his students found that these websites may not be completely lying but they also are misleading and do not include all the facts such as odds of having a certain genetic disorder. Some of the most questionable sites involved paternity testing.

The genetic counselor consulted during this project was Karen Kovac of OHSU.

Stigma Discrimination & Mental Illness Conference - Trish Backlar

Hundreds of people came to the conference held at PSU. People who came felt that it was a very emotional subject. She tried to have panel represent the different perspectives of providers, family members, and patients.

Trish was initially concerned with the issue of those with dangerous propensities who are mentally ill because this is an area where our fears may be justified in some way. Keeping things private may not always be the best route. She theorizes that sometimes hiding things can make things seem more mysterious and allow greater harm to occur. Trish thinks the issue of violence, the small percentage of persons with mental illness who commit violence, is probably not as unpredictable as people think. She feels that if there were better support for people who have mental illness, perhaps the situation would be different.

IRB Forum – Kara Manning-Drolet

Kara passed out handouts from the IRB Forum. She thinks it went really well. She noted that there was confusion on the notification requirement. There was also confusion on what you do for example if someone opts out then signs a consent form later. The notification requirement puts an even greater burden on IRB's and researchers to figure that out. At the end there was a case study discussion. There were several different institutions there. Everyone had a different opinion. They simply agreed that no one could agree what genetic research is.

Provider fact sheet and consumer facts sheets are done - Bob Nystrom

The final two fact sheets are being developed. He is willing to work on a very simple version of the consumer fact sheet, but it would be difficult to do this if no one agrees on the simplicity of the language. The DHS document will be available as a PDF with the DHS logo. A word version without DHS logo will also be posted so that it can be changed by whoever wants to.

Gwen Dayton said that OAHHS will be working on writing a script to give to admissions people in hospitals and medical facilities.

Outcome:

- Bob and Kerry will continue to work on the last two fact sheets.
- Naomi will post the consumer and provider fact sheets on line – one is PDF format, and one in word that will be editable and does not have the DHS logo.

SB 99 - Michael Garland and Gwen Dayton.

The concern with SB99 the first time was that Oregon's genetic privacy statute complicated the application of HIPAA regulations and therefore might hinder the ability of institutions to operate efficiently. People were concerned that providers would not be able to share information among physicians for treatment purposes, or in billing because the individual is usually long gone. Without authorization by the patient, insurers would not pay providers.

If ACGPR hopes to resubmit SB99 to the 2007 Legislature, it is very important to start now and meet with legislators to educate them about what the ACGPR hopes to accomplish and why.

Mike Garland feels that if the group is ready to commit to this bill again, and if the committee can identify the right champion in the legislature it would be reasonable to try again. However it is important to lay the issues out clearly for all the key legislators in advance of the session.

Mike Garland took a straw vote to see how the group felt about moving forward with SB99. Most of those present were in favor of moving forward Stuart Kaplan indicated that he needs to talk to his ACLU colleagues Andrea Meyer and Dave Fidanque before saying yes or no. Bob Nystrom noted that the new SB99 would not be a DHS sponsored bill. He abstained from voting.

Adjourned

Next Meeting June 7, 2006

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

Oregon Medical Association

5210 S.W. Corbett Avenue in Portland