

## Advisory Committee on Genetic Privacy and Research

Meeting Minutes – October 6, 2010

PSOB 1:30-3:00

**FINAL**

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### **Attendees:**

*Members:* Kara Manning Drolet, Anne Greer, Steve Nemirow, Nan Newell, Gayle Woods (phone), Ken Gatter, Trish Backlar

*Alternate Members:* Stuart Kaplan, Ted Falk (phone), Greg Fowler

*DHS staff:* none

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1. September 2010 minutes approved without revisions
2. Greg Fowler and Steve Nemirow agreed to be temporary co-chairs during Kara's maternity leave, probably December – February 2011. It was determined that since this is a temporary situation, there was no need for nominations or voting. Trish Backlar remains as co-chair.
3. Continued discussion of committee purpose
  - 1) Ted and Greg were offered an opportunity to share their points of view on the current purpose of the Committee
    1. Ted:
      - a. When the Committee was formed, the Legislature saw an urgent need to balance genetic privacy and research. Since that time, the Committee has done a lot of work has been done on this topic, including informing consumers about genetic testing.
      - b. Now, there are no urgent legislative issues requiring the Committee's work. The issues the Committee has examined recently, such as direct-to-consumer testing and GINA/Oregon reconciliation, do not appear to require legislative action, and the Committee has not identified other issues to work on. There will be issues in the future, but it is unclear that a policy committee will be needed to address them.
      - c. Given the lack of urgency and lower attendance, Ted proposed that a recommendation be made to the Legislature to disband the Committee. [At this point Ted lost the conference call connection.]
    - 2) Greg (and Trish):
      1. The Committee should reinvent itself to respond to future uncertainty in genetics progress and build on its education mandate, including educating

legislators.

2. The Committee hasn't finished its work on creating a new genetics privacy concept that emphasizes the importance of research.

b. Discussion and consensus/conclusions:

- 1) The Committee will NOT recommend that it be disbanded. It needs to continue to identify and study issues and make legislative recommendations when it deems necessary.
- 2) The current charter does not need to be changed.
- 3) The Committee needs to be more proactive in identifying and researching new genetic issues. Ones identified include epigenetics and testing student athletes for sickle cell trait.
- 4) Committee members will continue to volunteer their time to do the work needed.
- 5) The Committee needs to find out what our legislators are interested in.
- 6) There is still a need to reconcile GINA and OGPL.
- 7) Agenda items need to have concrete discussions with goals.
- 8) Since Committee members are identified at the beginning of each legislative session, this is a good time to expand the membership.
- 9) The meeting will return to every other month, beginning December, same time, same place. (A vote was taken: 7 for, 2 against)

4. Action items:

a. For December meeting

- 1) Trish and Greg to talk to four legislators: Dennis Richardson, Mitch Greenlick, Diane Rosenbaum, and Alan Bates. Report on their interests and issues for the Committee.
- 2) Nan to present a draft outline of the next legislative report.
- 3) Trish and Steve to meet with Jenny Franks about joining the Committee.

b. For February meeting

- 1) Katrina to lead a discussion on sickle cell trait testing in student athletes. She and Nan will send out background papers.

5. Adjourn

<p style="text-align: center;"><b>NEXT MEETING DECEMBER 1, 2010</b></p>
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