

Advisory Committee on Genetic Privacy and Research
Meeting Minutes – September 1, 2010

FINAL

Attendees:

Members: Kara Manning Drolet, Anne Greer, Steve Nemirow, Nan Newell, Gayle Woods, Ken Gatter

Alternate Members: Stuart Kaplan

DHS staff: Bob Nystrom, Nicoleta Voian

1. Introductions and Welcome to Ken Gatter. Ken is taking the seat that Ron Marcum held, representing “Licensed Physicians.” Ken is a pathologist at OHSU.
2. The May 2010 minutes were revised and approved.
3. Discussion of the upcoming report to the Legislature – Recommendations:
 - a. There is important work to be done, but there is no funding. Important work, at a minimum, includes comparison of OGPL and federal laws and public education.
 - b. Comparison of OGPL and federal laws (i.e., GINA, HIPAA, new health care law) – The committee discussed two approaches, both requiring methodological study:
 - 1) Compare the laws by doing a preemption analysis as discussed at previous meetings and make recommendations to the Legislature that would make the Oregon laws copacetic with the federal laws.
 - 2) Recommend that Oregon keep only the parts of Oregon law that we want and that supersede federal laws. The committee discussed two parts of Oregon law that would require discussion under this approach: the opt-out notice and the state’s insurance enforcement rights. Although this approach would probably be easier, it would also imply giving up “state’s rights,” which could be an issue politically.
 - c. On the cover page of the report, state what we can and cannot do as a committee with the resources we currently have.
4. Discussion of meeting time/place and membership/attendance.

- a. Discussed Ted Falk's and Greg Fowler's emails (attached to minutes); agreed that the nature of the committee has changed.
- b. Agreed that at the next committee meeting, the major agenda item would be to start to redefine the committee. It would be helpful for Ted and Greg to attend to express their views in person. We can also revisit the location, time, and frequency of the meetings. There are three options for beginning the discussion:
 - 1) Recommend to the Legislature that the committee be disbanded
 - 2) Recommend to the Legislature that the committee's charge be changed, and propose a new charter
 - 3) Keep the committee as is

5. Adjourn

<p style="text-align: center;">NEXT MEETING OCTOBER 6, 2010</p>
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