

Advisory Committee on Genetic Privacy and Research

February 2, 2011

1:30 – 3:00 pm

Portland State Office Building - Room 1D
800 NE Oregon Street, Portland, OR 97232

FINAL

Attending:

Members: K. Drolet, K. Gatter, K. Goddard, J. Franks, P. Backlar, S. Kaplan, N. Newell

Alternates: G. Fowler

OHA Genetics staff: B. Nystrom, S. Cox

Guest: Eran Klein (OHSU geriatric neurology, background in philosophy, working with P. Backlar on medical ethics)

1. December 2010 minutes approved with changes.
2. Discussion of DRAFT 2011 Legislative Report – Many changes were suggested. Nan will make the changes and send another draft for review.
3. Trish reminded us of the relevance of GINA to our Oregon law and to (in general) issues of discrimination as relevant to 'access' to health care, and that we will probably need to revisit it over time.
4. Committee roster for 2011-2013. Tabled due to lack of time.
5. Sickle cell testing and athletics –Katrina Goddard

Katrina presented a background to the issue of testing students' DNA in a number of settings, including the NCAA requirement that Division I athletes be tested for sickle cell trait, the proposed testing of all entering freshmen at UC Berkeley for three traits, and a class at Stanford where students can sequence their own DNA. Several issues were raised, including whether the testing is medically necessary, genetic counseling is provided, undefined consequences of mandatory testing, compliance with Oregon's informed consent

policies, testing of minors, who has access to the results, consequences of testing, and ADA compliance.

Oregon Genetics Program will do an initial inquiry on how PSU, OSU, UO, and UP are complying with the NCAA requirement before the next meeting.

6. Adjourn

Next Meeting

April 6, 2011

1:30-3:00