

**Advisory Committee on Genetic Privacy and Research
FINAL Minutes**

June 1, 2011
1:30 – 3:00 pm

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

Attendees

Members: Anne Greer, Hillary Booth, Laura Zukowski, Patricia Backlar, Stuart Kaplan

Alternates: Beth Crane, Eran Klein, John Sorensen, Karen E. Cooper, MaiKia Moua,

OHA Genetics staff: Bob Nystrom, Bridget Roemmich, Summer Cox

Members Not Present

Members: Gayle Woods, Jenny Franks, Kara Drolet, Katrina Goddard, Ken Gatter, Steve Nemirow

Alternates: Allison Naleway, Andrea Meyer, Gregory Fowler, Janie McGee, Paul B. Dorsey, Rhonda I. Saunders-Ricks, Terry Crandall

1. Introductions, including Bridget Roemmich, interim Genetics Program coordinator.
2. Review of agenda and approval of minutes for April 2011.
3. Unanimous vote to appoint Steve Nemirow and Stuart Kaplan as alternate co-chairs.
4. Discussion of sickle cell trait testing letter to Oregon NCAA Division 1 Athletic Directors.
 - a. Letter and attachments to be sent via email and United States Postal Service.
 - Attachments: ORS 192.529 through 192.549, Appendix 1, and ORS 192.522 Authorization Form
 - Letter will not be on letter head and will come from the ACGPR (Kara Drolet, as co-chair)
 - Committee may want to consider following up with schools to see if any practice or policy has changed
 - b. Trish urges committee to adopt a principle of population testing so that no particular group is targeted, and testing of any disease or trait cannot be used for discrimination.
 - Trish will forward 2 -3 articles pertaining to this subject for distribution to the entire committee
 - Committee agrees that to their best knowledge, in the case of sickle cell trait, all four schools (OSU, PSU, UofO, and UofP) are currently testing all student athletes (if they are testing at all) and are not targeting any specific group.

- Bob reminds committee that with limited resources, current medical policy is moving towards the use of targeted testing on high risk populations. A balance is needed between population based approaches and targeted testing as public health tools.
- Stuart reminds the committee that populations have been and continue to be targeted by gender, race, age, etc, and that when this is and is not appropriate may be a topic for the committee to discuss in the future.

5. Update from Bob regarding committee communication with legislature.

- a. The legislative policy committees have closed as of today (6/1/2011).
- b. Katy King (OHA legislative liaison) redirected Bob's questions to Office of Family Health administrator (Katherine Bradley). Katherine would like to discuss the possibility of a Public Health lawyer doing the ACGPR recommended analysis. If this is not possible, the request for Legislative Counsel to conduct the analysis can be made by Katy during the short session in February. Any legislator with interest in these matters should contact Katy King.
- c. Committee should be aware that legislative representatives have not yet been assigned to the ACGPR.

6. Brief updates about issues the committee has been tracking and an invitation for members to identify other genetic issues of interest.

- a. Laura brought up an interest in Health Information Exchanges (HIE), the opt-out model of participation and genetic privacy.
 - Anne is actively involved in the Legal & Policy Workgroup of the Oregon Health Information Technology Oversight Council (HITOC)
 1. Discussion of what the consent model should be for this type of information sharing is ongoing and made more complex by the inclusion of specially protected information (HIV status, genetics, substance abuse, and mental health).
 2. In Oregon, HIPAA allows information to be shared for the purposes of treatment (T), payment (P) and health care operations (O).
 3. There is a desire from stakeholders to both inspire consumer confidence in the protection of personal information and allow for a population based improvement of clinical care.
 - Stuart recommended that the committee continues to discuss the issues surrounding HIE, especially within the framework of the Oregon Genetics Law and how the committee might be able to help educate the public.
- b. The discussion of HIE and other genetic issues of interest were cut short due to the time and will recommence at the next committee meeting.

7. Adjourn

<p>Next Meeting August 3, 2011 1:30 – 3:00</p>
