

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

April 6, 2011  
1:30 – 3:00 pm

Portland State Office Building  
800 NE Oregon Street, Portland, OR 97232

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**Attendees**

Members: Kara Drolet, Jenny Franks, Ken Gatter, Anne Greer, Stuart Kaplan, Steve Nemirow (phone), Nan Newell

Alternates: Eran Klein

OHA Genetics staff: Bob Nystrom, Summer Cox

Guests: Hillary Booth, Karen E. Cooper, Janie McGee, MaiKia Moua, Laura Zukowski

**Members Not Present**

Members: Patricia Backlar, Katrina Goddard, Gayle Woods

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

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1. Introductions, including potential Committee members for “Oregon Health Authority, Public Health” and “Health Care Consumers.”
2. Review of agenda and approval of minutes for February 2011.
3. October 2010 minutes were approved by email prior to the 4/6/11 meeting.
4. Announcement of N. Newell’s retirement on April 8:
  - a. Members spoke to Nan’s great contributions to the committee and the pleasure they felt in serving with someone of such knowledge and humor.
  - b. Bob Nystrom reported on decision to not recruit for Nan’s position at this time; Summer Cox will assume day-to-day coordination of the Committee.
5. Legislative Report:
  - a. 2011 Legislative Report published and distributed in the manner provided by ORS 192.245.
  - b. Currently, there is no plan to present an informational hearing to the legislature or approach particular legislators. Bob Nystrom will speak with

Katy King to identify the best way to follow up with the legislative counsel on the committee's recommendation.

6. Review of information collected regarding Oregon universities and compliance with the NCAA requirement for sickle cell trait testing and athletics.
  - a. Several issues were raised, including: whether or not there are any negative ramifications to an athlete if they opt out; whether or not there are any student athletes who are positive on the teams; need for clarification on how policy is enacted; uncertainty about how are privacy and confidentiality protected in the student athlete setting.
  - b. Committee agreed that the university practices are not following the state law. Kara Drolet and Summer Cox will draft an informational letter to the OSU, OU, PSU and UP athletic directors; the letter will be emailed to committee for approval prior to sending.
7. Unanimous vote to restructure into an Alternate Co-Chair model of business:
  - a. New model of business: two co-chairs and two alternate co-chairs. The alternate co-chairs would participate in leadership of committee, such as pre-meeting conference calls and review of agenda, and lead the committee when a co-chair can not.
  - b. Kara Drolet & Patricia Backlar will remain as Co-Chairs
  - c. Steve Nemirow and Stuart Kaplan were nominated as alternative co-chairs; other nominations are welcome via email.
8. Unanimous vote to approve new committee members:
  - a. "Education and Ethics": Eran Klein as alternate.
  - b. "Oregon health Authority, Public Health": Hillary booth as member, Karen Cooper, Janie McGee, MaiKia Moua, John Sorensen and Jamie Walters will be invited to join as alternates.
  - c. "Health Care Consumer": Laura Zukowski as member, Beth Crane as alternate.
9. Next meeting: Brief updates about what issues the committee has been tracking and an invitation for members to identify other genetic issues of interest.
10. Adjourn

<p style="text-align: center;"><b>Next Meeting</b> <b>June 1, 2011</b> <b>1:30 – 3:00</b></p>
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