

June 22, 2005

Report to the 2005 Legislature

*Advisory Committee on Genetic
Privacy and Research*

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Executive Summary

The Advisory Committee on Genetic Privacy and Research (ACGPR) was appointed by the 2001 Oregon Legislature to study the use and disclosure of genetic information as regulated by Oregon law. In this report, the Committee recommends four changes to make the current law more consistent with federal medical information privacy statutes and Oregon public opinion.

1. Exempt routine disclosures of genetic information by providers and health insurers from special protections.
2. Prohibit use of blood relatives' medical history for health insurance and employment decisions.
3. Prohibit use of information concerning whether a person has sought genetic counseling for health insurance and employment decisions.
4. Modify informed consent requirements for research under certain limited circumstances.

The first of these recommendations is in SB99, submitted by the Department of Human Services. The other three recommendations are being brought to the Legislature as legislative proposals sponsored by the ACGPR.

The areas the Committee will focus on in the current biennium are:

1. Assess whether genetic exceptionalism continues to be an acceptable logical basis for genetic privacy and research policy in Oregon.
2. Monitor Oregon's genetic privacy law for unanticipated effects.
3. Participate, and support community partners, in efforts to monitor the consumer/public perspective on genetic privacy and research issues.

Introduction

The 2001 Oregon Legislature appointed the Advisory Committee on Genetic Privacy and Research (ACGPR) to study the use and disclosure of genetic information as regulated by Oregon law and make recommendations for change. The Committee was also charged with: collaborating with the Oregon Department of Human Services, Health Services, on administrative issues, including the process of adopting administrative rules and guidelines for genetic research; biennial reporting of Committee findings and recommendations to the Oregon Legislature; and creating opportunities for public education and eliciting public input on the challenging issues of genetic privacy and research. The Committee is composed of fifteen volunteer members and alternates appointed by the Senate President, Speaker of the House, and Assistant Director of the Department of Human Services for renewable two-year terms. The membership of this dynamic Committee represents the diversity of stakeholders in genetic privacy and research in Oregon.

In 2003, the Committee presented a comprehensive report¹ to the Legislature and recommended legislative changes that were subsequently adopted into Oregon statute.² Since then, enactment of the Health Insurance Portability and Accountability Act (HIPAA) prompted the Committee to review and propose additional changes to the Oregon law. The implementation of this Federal health information privacy law greatly improves the privacy of medical information, and genetic information by default.

The following report summarizes the Committee's 2004-2005 activities, sets forth its recommendations to the 2005 Legislature, and describes its proposed activities for 2006-2007.

¹ Full text of the 2003 ACGPR Legislative Report is available at <http://egov.oregon.gov/DHS/ph/genetics/docs/acgprprt.pdf>

² 2003 Oregon Senate Bill 618. See also ORS §192.531-549 and Section 8, chapter 588, Oregon Laws 2001.

Committee Activities and Recommendations

Senate Bill 618, passed by the Legislature during the 2003 legislative session, established a number of required elements to be researched for the 2005 legislative report. During the past biennium, the Committee inevitably could not take on all tasks assigned in the legislation. This report discusses each required element and reflects the Committee's priorities and recommendations.

Whether genetic privacy statutes can be simplified in light of HIPAA

The Federal health information privacy law, HIPAA (passed in 1996 and implemented in 2003), provides comprehensive protection for personal health information. Because genetic information is considered protected health information under the terms of HIPAA, the Committee reviewed HIPAA for duplications and gaps in protection between HIPAA and the Oregon genetic privacy law. The committee took advantage of the depth of expertise represented among ACGPR members, alternates, and guests to address this issue. HIPAA is extraordinarily complex, and the process to understand it was long and intensive. Committee leadership devoted several meetings solely to the complex issue of what duplications in protection are provided, and what gaps in protection remain between Federal statute and Oregon law. The outcome of these discussions is Recommendation 1, which addresses the need to streamline and simplify Oregon genetic privacy protections.

Recommendation 1: Exempt routine disclosures of genetic information by providers and health insurers from special protections. The Committee recommends that the Legislature pass legislation allowing the HIPAA privacy regulations and commensurate Oregon medical privacy laws to protect routine disclosures of genetic information by providers and health insurers. The special protections accorded genetic information are too broad and have restricted retention and disclosure of medical information in a manner that negatively affects patient care and necessary provider and insurer activities. The HIPAA privacy regulations and Oregon medical privacy laws protect medical information from inappropriate disclosure and will adequately protect routine disclosures of genetic information. This approach to genetic privacy is consistent with public opinion as expressed in a recent survey (discussed on page 7). Recommended changes to Oregon's genetic privacy statutes would:

1. Allow a health care provider or health care service contractor to retain an individual's genetic information without obtaining authorization if the retention is for the provider's own treatment, payment or health care operations;
2. Allow a health care provider or health care service contractor to disclose an individual's genetic information without obtaining an authorization if the provider discloses the genetic information in accordance with ORS 192.520(3);

3. Allow a health insurer to retain an individual's genetic information without obtaining an authorization if the retention is for the insurer's own treatment, payment, or health care operations;
4. Allow a health insurer to disclose an individual's genetic information without obtaining authorization if the insurer discloses the genetic information in accordance with ORS 746.607(3).

The Committee supports legislation (SB99) introduced by the Department of Human Services to make the changes outlined above.

Use of genetic information by insurers

The use of genetic information by health insurers was an essential aspect of the Committee's decision to arrive at Recommendation 1. In order to simplify Oregon law and make it consistent with HIPAA, health insurer access to genetic information was discussed in detail. The Committee concluded that health insurers must be able to access health information, including protected genetic information, for purposes of treatment, payment, and health care operations in order to engage in routine business practices. These activities are regulated by HIPAA, and under this federal health information privacy regulation, genetic information is protected to the same extent as other personal health information. The Committee felt that this protection is adequate to protect Oregon consumers, and this position is reflected in SB99.

Whether to include family history in the definition of genetic information

The Committee discussed whether to include family medical history in the definition of genetic information. The primary concern is the use of family medical information in decisions about health insurance and employment. Given the ubiquitous nature of family information in medical records, and the fact that family information is, in part, genetic information, changing the definition of genetic information may have unintended consequences. The Committee recommends addressing the concern directly by prohibiting use of medical history of blood relatives for health insurance and employment decisions.

Recommendation 2. Prohibit use of blood relatives' medical history for health insurance and employment decisions: The Committee recommends that the Legislature amend Oregon law to prohibit the use of blood relatives' medical history in health insurance and employment decisions.

Oregon law, as currently written, leaves the possibility of using a family history of a genetic condition that was not diagnosed through the use of a genetic test for health insurance and employment decisions. This leaves individuals unprotected for the vast majority of genetic disorders. Susceptibility to, or the presence of, genetic disorders can be diagnosed by a "genetic test" in only a minority of situations. Clinical examination and family history are much more widely used in

establishing susceptibility or disease. Thus, under current Oregon law, for example, a person can be denied employment or health insurance because he or she has a parent with Huntington disease if the diagnosis was made clinically, but not if the diagnosis was made by a genetic test (DNA test). The same is true for cancer, birth defects, and other disorders. The Committee proposes an amendment that will cover any “condition, disease, or disorder in blood relatives,” since genetic susceptibility contributes to most health care problems, and genetic contributions cannot be easily separated from non-genetic contributions to disease. The proposed wording is consistent with that used in existing³ and proposed⁴ Federal protections.

The Committee will introduce legislation in the 2005 biennium to prohibit use of blood relatives’ medical history for health insurance and employment decisions.

Discrimination involving an individual seeking genetic services

As proposed in the 2003 Legislative Report, the Committee considered gaps in protections against genetic discrimination, particularly in the act of seeking genetic counseling.⁵ An analysis of current Oregon law revealed a gap in protection for those seeking genetic counseling, and the Committee agrees that this gap should be closed. The Committee is concerned that individuals may be deterred from seeking genetic counseling because of a perceived risk of discrimination.

Recommendation 3. Prohibit use of information concerning whether a person has sought or received genetic counseling for health insurance and employment decisions. The Committee recommends that the Legislature amend Oregon law to make it unlawful to use information about seeking or receiving genetic counseling in health insurance and employment decisions.

Based on input from Committee members who are genetic health care providers, the Committee is concerned that individuals may be deterred from seeking genetic counseling for fear that an employer or health insurer will use such information against them in health insurance or employment decisions. Oregon genetic privacy law currently does not protect use of information about seeking or receiving genetic counseling. The Committee proposes an amendment to Oregon law ensuring health care consumers will not suffer adverse consequences in health insurance or employment as a result of seeking or receiving genetic counseling. The proposed wording is consistent with that used in existing⁶ and proposed⁷ Federal protections.

³ Executive Order No. 13145, 65 Fed. Reg. 6,877 (2000). *To Prohibit Discrimination in Federal Employment Based on Genetic Information.*

⁴ U.S. Senate, 109th Congress, 1st Session, S.306, *Genetic Information Nondiscrimination Act of 2005.* (Introduced 2/7/2005.) Online. Available: <http://thomas.loc.gov/cgi-bin/query/D?c109:2:./temp/~c109tHORWv>: [April 1, 2005]

⁵ See the 2003 Legislative Report, Recommendation 6. Available at: <http://egov.oregon.gov/DHS/ph/genetics/docs/acgprprt.pdf>

⁶ Executive Order 13145, 65 Fed. Reg. 6,877 (2000). *To Prohibit Discrimination in Federal Employment Based on Genetic Information.*

⁷ U.S. Senate, S.306, *Genetic Information Nondiscrimination Act of 2005.*

The Committee will sponsor legislation in the 2005 biennium that will prohibit using information about the request for, or receipt of, genetic services in employment decisions or to affect the terms and conditions of any insurance policy.

Procedures for protecting the subjects of genetic research

Under Federal law, institutions performing human subjects research must adhere to strict standards to protect research subjects. One essential element to human subjects protection is prior review and approval of research proposals by a committee with sufficient scientific, medical, ethical, and legal expertise to review the proposals. Committee members are drawn from the research community and from the community at large. Both Oregon law and Federal require this type of committee, known as an Institutional Review Board (IRB), to prospectively review all research protocols, including those involving genetic information. The IRB is charged with protecting the rights and welfare of human research subjects, and ensuring that any risks to the subjects are balanced by benefits from the research.

Voluntary informed consent is a second key element of protecting human research subjects. Written informed consent for participation in a research study is required under the Federal Common Rule, except in certain limited circumstances. An IRB can alter informed consent requirements if the following criteria are met (45 CFR 46.116).

1. The research involves no more than minimal risk to the subjects;
2. The waiver or alteration will not adversely affect the subjects' rights and welfare;
3. The research could not practicably be carried out without the waiver or alteration; and
4. The subjects will be provided with additional pertinent information after participation, whenever appropriate.

Under Oregon's genetic privacy law, all genetic research studies, whether publicly or privately funded, must receive prior approval by an IRB. Also under Oregon law, human research subjects must give informed consent for all genetic research except anonymous research. In the case of anonymous research, potential participants must be notified that anonymous research may occur and be given the option to decline being part of the study.

The standard of informed consent is particularly difficult to maintain in genetic research based in clinical care, because this type of research routinely uses information from medical records to answer scientific questions important to health care delivery. In clinical care, written consent is not routine except for certain procedures (such as surgery or amniocentesis). Written consent is routinely obtained for some genetic tests (such as presymptomatic or predispositional testing), but not for most genetic tests (such as diagnostic testing and carrier testing). Thus, it is difficult or impractical to obtain written informed consent for research in most clinical situations, because, according to Oregon law, genetic information that is generated as part of clinical care is treated differently than other medical information generated as part of care.

The Committee is concerned that research, and thus the benefit to the public, may be adversely affected by Oregon's genetic privacy law in situations in which research subjects already have adequate protection under HIPAA and the Federal Common Rule. The following amendment to Oregon's law extends to the IRB the ability to waive or alter

informed consent requirements if the IRB finds that risk to the subjects is minimal, the rights of the subjects are being safeguarded, and the research would not otherwise be practicable (see the criteria of 45CFR 46.116, above). These changes are intended to maintain protection for research subjects, maintain the benefits of research, and ensure a vigorous research environment in Oregon.

Recommendation 4. Modify requirements of informed consent for research under certain limited circumstances. The Committee recommends that the Legislature modify Oregon law to allow use of genetic information and DNA samples in coded research without requiring blanket or specific consent, as specified under Oregon law, if the responsible IRB finds the study meets Federal requirements to alter the informed consent process. The Committee recommends that the Legislature allow the HIPAA Privacy Regulations and the Federal Common Rule to protect retention, disclosure, and use of genetic information and DNA samples in research if the responsible IRB finds the study meets the requirements to alter the informed consent process under 45 CFR 46.116.

Based on input from health researchers, the Committee is concerned that the special protections accorded genetic information and DNA specimens have restricted use of genetic information and DNA specimens in a manner that negatively affects research and the potential for public benefit from such research. Changing Oregon's law in this way will protect research subjects whose information or specimens are part of a minimal risk study and maintain the benefits of such research.

With the sponsorship of the Committee, legislation was introduced (SB1025) that will allow the use of genetic information and DNA samples in coded research under the described conditions.

The Committee also discussed the need for a more comprehensive assessment of Oregon's law as it relates to research and the protection of research subjects, while considering newer Federal regulations (such as HIPAA) and additional feedback from researchers. This issue will be discussed in the future.

Informed consent as applied to DNA samples and genetic information

The legal principle of informed consent is an integral component of most discussions relating to genetic research and the privacy of genetic information,⁸ one that arises frequently in discussions of differences between Oregon genetic privacy law and HIPAA. The Committee decided that because of the conceptual, legal, and philosophical complexity of the concept, this element is a low priority for future discussion and Committee action, except as it arises in the context of other higher-priority issues like research and health care.

⁸ For a discussion of this issue, see the 2003 Legislative Report, p.5. Available at: <http://egov.oregon.gov/DHS/ph/genetics/docs/acgprprt.pdf>

Patenting of human genes

As recommended in the 2003 report, the Committee sought funding to facilitate research into the role Oregon should play in the patenting of human genes. No funding sources were identified and leadership decided that due to the complexity of this area of law, and because of the low perceived impact on Oregon genetic privacy, health care, and research, this element was given a marginal priority. No further action was undertaken in this biennium.

Genetic testing

The Committee did not specifically address the topic of genetic testing during the 2003-05 biennium. Genetic testing has been a low priority topic, partially due to the non-specific nature of the proposed discussion topic, the potential enormity of scope, and the relatively higher priority and immediate importance of the other topics.

Public education and input

In addition to the elements addressed above, the Committee was also required to “create opportunities for public education on the scientific, legal, and ethical development within the fields of genetic privacy and research...[and to] elicit public input on these matters.” To these ends, the Committee is engaged in several activities and has made the following progress.

A civic organization, Geneforum.org, provided assistance to the Committee by designing and funding a random sample telephone survey of 604 Oregonians that was conducted by Market Decisions Corporation of Portland in August 2004.⁹ The Committee provided input to the content of the survey so that the findings would relate to the issues on the Committee’s agenda. The survey probed four topics of special concern to the Committee: (1) the relationship between privacy and discrimination in the public’s concerns about genetic information; (2) how the public views genetic information compared to other forms of health information; (3) how Oregonians think about genetic counseling and privacy; and (4) the relative importance Oregonians assign to preventing insurers from using genetic information to base price or coverage decisions. The results of the survey are:

1. *Privacy and Discrimination.* Most respondents are concerned about privacy of genetic information. More respondents are concerned about privacy for its own sake than about potential discriminatory use. Among uninsured persons, however, concern about discriminatory use of genetic information was equal to privacy for its own sake.
2. *Special status of genetic information.* When asked in a general way, respondents indicate that it is no more important to protect the privacy of genetic information than it is to protect the privacy of other forms of medical information. This judgment is more pronounced among respondents with higher levels of knowledge about genetics. When asked more specific questions comparing

⁹ Survey questions are included in Appendix II. For more details about this survey, see www.geneforum.org or contact Greg Fowler, Ph.D., Executive Director, Geneforum. E-mail: gfwler@geneforum.org; T: 503-636-3627

particular types of medical and genetic information using two serious medical conditions as examples, the majority still did not think that genetic information was more important to keep private than other kinds of health information. Many respondents, however, gave different answers to these two specific questions than they did to the general question about the privacy of genetic information.

3. *Genetic Counseling.* Respondents indicated similar importance for protecting the privacy of genetic counseling and other specific kinds of medical information.
4. *Use of genetic information by insurers.* Respondents gave higher priority to preventing insurance carriers from basing price or coverage decisions on genetic information with respect to health insurance than either disability insurance or life insurance. They gave equal priority to preventing such use in relation to decisions about disability and life insurance.

Portland State University has been an active partner with the ACGPR in efforts to engage the community in educational dialogue about issues related to genetics, genetic technology, and associated ethical issues. Committee members recently partnered with locally- and nationally-known experts to provide educational opportunities for Oregonians. One such event was a free public symposium,¹⁰ entitled “Genetic Testing, Privacy, and Race,” that took place in April 2005. The ACGPR and several other community-based stakeholders sponsored this event, which drew a full-capacity audience of over 200. In addition to this symposium, a more formal educational opportunity is available to students at PSU. A local non-profit organization, Geneforum.org, works with PSU to teach a quarter-long senior capstone course called “Democracy, Ethics, and Civic Discourse in the Gene Age.” The course engages students and community experts (including many ACGPR members) in a participatory democratic model that educates students to ensure that public policy reflects the values of an informed public. The course culminates in an annual public forum, hosted and planned by students, in which students seek to engage the larger campus community in discussions about priority issues related to genetics and policy.¹¹

The Genetics Program at the Oregon Department of Human Services also seeks to fulfill the public education obligation of the ACGPR through its program activities. In particular, the Genetics Program maintains a website¹² that provides members of the public with educational materials related to public health and genetics, genetic privacy and research, and resources for consumers and health care providers. Extensive information about genetic privacy law in Oregon and the proceedings of the ACGPR are available at this site.

¹⁰ See Appendix III for more information

¹¹ See Appendix IV for more information

¹² <http://egov.oregon.gov/DHS/ph/genetics/index.shtml>

Moving Forward – Next Steps

In the future, the Committee anticipates an ongoing need for discussion about policy issues related to genetic privacy and research in Oregon. Assuming passage of Recommendations 1-4, the Committee proposes to continue its work into the next biennium, 2005-2007, prioritizing the following areas for discussion:

1. Assess whether genetic exceptionalism continues to be an acceptable logical basis for genetic privacy and research policy in Oregon, considering protections provided by Federal legislation such as HIPAA. Oregon's law is based on genetic exceptionalism, a principle that holds that genetic information differs from other clinical or medical information. The results of the Geneforum survey and opinions expressed in the literature about public policy and genetics indicate that this is an important question for the Committee to take up at this point. If relevant, recommend legislative action to change Oregon's genetic privacy law.
2. Monitor Oregon's genetic privacy law for unanticipated effects. Be prepared to recommend legislative action to remedy unanticipated problems, if needed.
3. Continue to participate in and support community partners in efforts to monitor the consumer/public perspective on genetic privacy and research issues.

APPENDIX I: Member Roster 2004-2005

Advisory Committee on Genetic Privacy and Research

Senate President's Representatives

Member

Senator Richard Devlin
Phone (503) 986-1719
E-Mail sen.richarddevlin@state.or.us

Alternate

VACANT

Speaker of the House's Representatives

Member

Representative Dennis Richardson
Phone (503) 986-1404
E-Mail rep.dennisrichardson@state.or.us

Alternate

Representative Gordon Anderson
Phone (503) 986-1403
E-Mail rep.gordonanderson@state.or.us

Academic institutions involved in genetic research

Member

Robb Moses, MD
Chair, Department of Medical Genetics
Oregon Health & Science University
Phone (503) 494-6881
E-Mail mosesr@ohsu.edu

Alternate

Robert Koler, MD
Associate Vice President Emeritus
Oregon Health & Science University
Phone (503) 494-5007
E-Mail koler@ohsu.edu

Licensed physicians

Member

Jonathan Zonana, MD
Professor, Departments of Molecular and Medical
Genetics and Pediatrics
Oregon Health & Science University
Phone (503) 494-4448
E-Mail zonanaj@ohsu.edu

Alternate

George Anadiotis, DO
Physician, Legacy Emanuel Hospital
Pediatric Development & Rehabilitation
Phone (503) 413-4505
E-Mail ganadiot@lhs.org

Voluntary organizations: Genetic privacy policy development

Member

Marc Marenco, PhD, Director
Pacific Institute for Ethics and Social Policy
Pacific University
Phone (503) 352-2296
E-Mail marencom@pacificu.edu

Alternate

Theodore Falk, JD, PhD
Phone (503) 947-4510
E-Mail theodore.c.falk@state.or.us

Hospitals

Member

Gwen Dayton, JD
Vice President and General Counsel
Oregon Association of Hospitals
and Health Systems
Phone (503) 636-2204
E-Mail gdayton@oahhs.org

Alternate

Rita Aikins
Oregon Region
System Director Privacy/SIS Security
Providence Health System
Phone (503) 216-5467
E-Mail rita.aikins@providence.org

Department of Human Services, Health Services

Member

Nanette Newell, PhD
Assistant Manager
Public Health Preparedness
Oregon Department of Human Services
Phone (503) 731-4437 ext. 250
E-Mail nanette.newell@state.or.us

Alternate

Cheryl Hermerath
Newborn Screening Manager
Oregon Public Health Laboratories
Phone (503) 229-5882
E-Mail cheryl.a.hermerath@state.or.us

Department of Consumer and Business Services

Member

Gayle Woods
Manager, Rates and Forms
Department of Consumer and Business
Services
Phone (503) 947-7270
E-Mail gayle.woods@state.or.us

Alternate

Lewis Littlehales
Senior Policy Analyst
Department of Consumer and Business
Services
Phone (503) 947-7234
E-Mail lewis.c.littlehales@state.or.us

Health care service contractors: genetic and health services research

Member

Emily Harris, MPH, PhD
Senior Investigator
Kaiser Permanente Center for Health Research
Phone (503) 335-2419
E-Mail emily.harris@kpchr.org

Alternate

Margo Neufeld, JD
Senior Counsel
Kaiser Foundation Health Plan
Phone (503) 813-3988
E-Mail margaret.r.neufeld@kp.org

Biosciences industry

Member

Carol Pratt, PhD, JD
Preston | Gates | Ellis LLP
Phone (503) 226-5762
E-Mail cpratt@prestongates.com

Alternate

Mya Thomae

E-Mail mya@myathomae.com

Pharmaceutical industry

Member

Mark Loveless, MD
Virology Medical Liaison
Scientific Field Operations
Roche Labs, Inc.
Cell Phone (preferred): 503-939-1889
E-Mail Mark.Loveless@roche.com

Alternate

TBD

Health care consumers

Member

Margaret Everett, PhD
Department of Anthropology
Portland State University
Phone (503) 725-3319
E-Mail everettm@pdx.edu

Alternate

Marilyn Hartzell, M.Ed.
Child Development & Rehabilitation Center
Oregon Health & Science University
Phone (503) 494-
E-Mail hartzell@ohsu.edu

Organizations advocating for privacy of medical information

Member

Stuart Kaplan, PhD
ACLU-Oregon Board Member
Phone (503) 768-7618
E-Mail skaplan@lclark.edu

Alternate

Andrea Meyer
Legislative Director/Counsel
ACLU-Oregon
Phone (503) 227-6298
E-Mail ameyer@aclu-or.org

Public members of institutional review boards

Member

Victor Leo
Public Member
Oregon DHS-HS IRB
Phone (503) 788-8778
E-Mail victorleo@hotmail.com

Alternate

Paul Newton, JD
Attorney
Oregon DHS-HS IRB
Metropolitan Public Defender
Phone (503) 273-8213
E-Mail pnewton@mpdlaw.com

Education and ethics

Member

Mike Garland, Professor Emeritus
Oregon Health & Science University
Department of Public Health & Preventive
Medicine
Phone (503) 236-1293
E-Mail mdgar@teleport.com

Alternate

Patricia Backlar
Associate Professor of Bioethics
Portland State University
Department of Philosophy
Phone (503) 725-3499
E-Mail backlarp@pdx.edu

2nd Alternate

Gregory Fowler, PhD
Executive Director, Geneforum
Phone (503) 675-0772
E-Mail gfwler@geneforum.org

DHS Committee Staff

Oregon Department of Human Services
Health Services
800 NE Oregon Street, Suite 825
Portland, Oregon 97232

Kiley Ariail, MPH (*Committee Facilitator*)
Genetics Program Coordinator
Phone (971) 673-0272
E-Mail kiley.ariail@state.or.us

Bob Nystrom, MA
Adolescent Health Manager and Genetics Program
Manager
Phone (971) 673-0243
E-Mail robert.j.nystrom@state.or.us

Naomi Adams
Administrative Specialist
Phone (971) 673-0271
E-Mail naomi.adams@state.or.us

Interested Participants

Bob Shoemaker, JD
Oregon Genetic Privacy Advisory Committee
Phone (503) 223-6691
E-Mail rcshoe@aol.com

Kerry Silvey, MA, CGC
Genetic Services Specialist
CDRC – Clinical Services Building
Phone (541) 346-2610
E-Mail ksilvey@oregon.uoregon.edu

Peter Jacky, PhD, FACMG
Director, Cytogenetics & Molecular Genetics
Kaiser Permanente, NW RLB
Phone (503) 571-5633
E-Mail peter.jacky@kp.org

Mary L. Durham, PhD
Director, KP Center for Health Research
Vice-President, Research
Kaiser Foundation Hospitals
Phone (503) 335-6677
E-Mail mary.durham@kpchr.org

Kara Manning, Ph.D.
Assistant Compliance Officer
Oregon Health & Science University
E-Mail manningk@ohsu.edu

Lisa Sardinia, PhD, JD
Pacific University
Phone (503) 352-2242
E-Mail sardinil@pacificu.edu

Ronald G. Marcum, M.D.
Oregon Health & Science University
Department of Obstetrics and Gynecology
Phone (503) 494-1710
E-Mail marcumr@ohsu.edu

APPENDIX II

Public Education and Input: GENEFORUM Public Input Survey 2004

Issue One: Privacy of Genetic Information

- Q1.** I am going to read two statements. For each, please tell me whether you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree or strongly disagree with the statement. (Rotate the order of statements)
- A. I am concerned about keeping my genetic information private because someone might use it to discriminate against me.
 - B. I am concerned about keeping my genetic information private because it's private. I don't want anyone else to see it without my permission.

Issue Two: The Relative Importance of the Privacy of Genetic Information

- Q2.** Now, I'm going to read you two statements about protecting the privacy of personal health information. Please tell me which one comes closer to your opinion. (Rotate the order of statements)
- A. I think it is more important to protect the privacy of genetic information than it is to protect the privacy of other kinds of health information. OR
 - B. Genetic information is a kind of health information and I think the privacy of all kinds of health information should be protected equally.
- Q3.** Now I'm going to read you two statements about tissue samples of a person's body that physicians sometimes use for diagnostic tests. Some companies that do medical research request a portion of such samples from physicians so they can do further research using the tissue samples. This research usually has nothing to do with the person's medical care. Please tell me which of the following statements comes closer to your opinion. (Rotate order of statements)
- A. I am more concerned about privacy when my tissue sample will be used for genetic research than when it will be used for other kinds of research. OR
 - B. I am equally concerned about privacy whether my tissue sample will be used for genetic research or for other kinds of medical research.
- Q4.** Now I will mention several kinds of private information that might be in a person's medical record. For each, please tell me how important it is to protect the privacy of that specific kind of information. Please use a scale from 1 to 5, where five (5) means it is "very important" and one (1) means it is "not important at all." (Rotate order of statements)
- A. Whether a person has been diagnosed with HIV disease
 - B. Whether a person has a diagnosis of high blood pressure
 - C. Whether a woman is pregnant
 - D. Whether a person sought genetic counseling
- Q5.** Now, suppose there are three kinds of information about colon cancer that might be in a person's medical record. Please tell me which kind of information you would MOST want to keep private.
- A. Whether a person has a diagnosis of colon cancer. OR
 - B. Whether, based on family history, a person is more likely than other people to develop colon cancer. OR
 - C. Whether, based on a positive genetic test, a person is more likely than other people to develop colon cancer.

D. All are equal

Q6. Now, I'll ask the same thing about a different disease – Alzheimer's Disease. Please tell me which kind of information you would most want to keep private.

- A. Whether a person has a diagnosis of Alzheimer's disease. OR
- B. Whether, based on family history, a person is more likely than other people to develop Alzheimer's disease. OR
- C. Whether, based on a positive genetic test, a person is more likely than other people to develop Alzheimer's disease.
- D. All are equal

Issue Three: Use of Genetic Information by Insurers

Q7. Suppose you had \$100 to invest in a program to prevent three kinds of insurance carriers from using genetic information to set prices or deny coverage: The insurance carriers are 1) health insurers, 2) disability insurers, and 3) life insurers. Please tell me how much or what percentage of the \$100 you would spend on each of the three kinds of insurance carriers.

- A. How much of the \$100 would you invest to prevent health insurers from using genetic information to set prices for health insurance or deny coverage?
- B. How much of the \$100 for disability insurance (which provides temporary income replacement in the event of a disabling injury or illness)?
- C. How much of the \$100 for life insurance?

Issue Four: General Knowledge about Genetics

Q8. Scientists have discovered that some diseases happen to people who have specific changes in the structure of one or more of their genes. Please tell me whether you think the following statements are true or false.

- A. If a person has one of these diseases, it means that any children the person has will also have the disease.
- B. People who are carriers of such genetic changes will usually develop the condition if they live long enough.

Q9. I'm going to read some statements about changes that can take place in a person's DNA, the molecules inside a person's cells that carry genetic information. Scientists call these changes in DNA "gene mutations." For each statement, please tell me whether you think it is true or false.

- A. Everyone has some gene mutations.
- B. Gene mutations always cause health problems.

FREE PUBLIC SYMPOSIUM

Genetic Testing, Privacy and Race

Thursday,
March 31, 2005
5:30-7:30 p.m

Portland State University
Lincoln Hall, Room 75
1620 SW Park

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OFFICE OF MULTICULTURAL HEALTH, OREGON DEPARTMENT OF HEALTH SERVICES

GENEFORUM www.geneforum.org

In this symposium, panelists will examine two types of cases: **Genetic Testing and the Criminal Justice System** (the forensic uses of DNA technologies to construct genetic profiles or fingerprints); and **Genetic Testing and the Medicalization of Race**.

PANELISTS

Troy Duster, Ph.D.

Chancellor's Professor at the University of California, Berkeley, and Professor of Sociology and Director of the Institute for the History of the Production of Knowledge, New York University. Professor Duster is currently president of the American Sociological Association. His book, *Backdoor to Eugenics*, is in its second edition, and he is co-author of *Whitewashing Race: the Myth of a Colorblind Society*, 2004.

Susan Olson, Ph.D.

Professor of Molecular and Medical Genetics, Director of the Cytogenetics Laboratory, OHSU

Nancy Press, Ph.D.

Professor of Medical Anthropology, School of Medicine and School of Nursing, OHSU

Paul Newton, J.D.

Attorney Supervisor of Special Courts Section (Arraignments, Civil Commitments, Drug Court, Community Court) Metropolitan Public Defender Inc., Portland

Jon Zonana, M.D.

Professor and Director of Clinical Genetics, Department of Molecular and Medical Genetics, OHSU

MODERATOR

Marc Marengo, D.Phil.

Associate Professor of Moral Philosophy and Director, Pacific Institute for Ethics and Social Policy at Pacific University

PROGRAM DIRECTOR

Patricia Backlar

Research Associate Professor of Bioethics, Department of Philosophy, PSU; Senior Scholar, Center for Ethics in Health Care, and Adjunct Assistant Professor of Bioethics, Department of Psychiatry, OHSU

“Democracy, Ethics, and Civic Discourse in the Gene Age”

***A Winter 2005 Capstone Course
6 credits***

The genetic revolution of the 21st century will affect every aspect of our lives: the food we eat, the way we have our babies, raise and educate our children, work, engage in politics, fight disease, express our faith, and perceive the world around us and our place in it.

Using the Geneforum democratic model of public education, public engagement and public consultation, capstone students will learn methods for **1)** developing objective educational materials (public education); **2)** engaging the public in dialogue (public engagement); and **3)** transmitting public values to the policy process (public consultation) about the science behind the new genetic technologies and the ethical issues they raise. In the process, students will gain critical thinking and listening skills and an appreciation for tolerance and respect for other points of view.

For more information see www.geneforum.org or call 503-636-3627.

***Gregory Fowler, Ph.D., Adjunct Professor of Biology,
Portland State University, and Founder and Executive
Director, Geneforum***

geneforum
Informing Citizens for the Gene Age