

Oregon's Strategic Plan for Genetics and Public Health

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Scientists announced the formal completion of the human genome — a milestone marking the end of the first chapter of the genetics revolution and the dawn of a second, even more arduous chapter, figuring out the meaning of it all.

The next challenge will stretch into the decades to come: determining the function of all 3 billion DNA letters in the human genetic code and understanding how those letters direct growth, life, reproduction, disease and death.

— Rosie Mestel
LA Times-Washington Post Service
April 14, 2003

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Overview

Rapid technological advances in the field of genetics and the potential impact of these advances on individual and population health make this area a high priority for public health consideration and planning. It is envisioned that as the role of genetics in many, if not most health processes, is further delineated, there will be marked changes in the scope and nature of genetics services as well as genetic information and policy needs. Though Oregon has had a number of excellent programs and resources to serve individuals and families impacted by inherited conditions and other special health needs, a comprehensive and coordinated effort addressing genetics and public health was needed.

Recognizing the emerging importance of genetics for public health, the Oregon Department of Human Services-Office of Family Health and the Child Development and Rehabilitation Center at Oregon Health & Science University applied for and received a two-year federal grant from the HRSA Maternal and Child Health Bureau to conduct an assessment of Oregon's genetic health care system and develop a state public health plan to improve existing or develop new genetic health services and resources. The assessment and planning process began in June 2000 and was carried out by state Genetics Program staff with guidance from the Genetics Plan Advisory Council, a broad-based group of state and community partners. Program staff used the "ten essential services of public health" as a framework for the assessment process. Issues such as health data collection and analysis, public information and education, health care workforce competency, health services access and quality, health policy development, research and partnerships were all addressed from a "genetics" perspective. The assessment included a comprehensive inventory of current genetic health services and resources as well as an array of community assessment activities (e.g., interviews, surveys, focus groups and other group processes) with diverse stakeholders. Using assessment findings, a strategic plan was developed to guide the activities of the State Genetics Program and its partners over the next 3-5 years.

Key assessment findings included:

- ▲ An identified need to increase public health capacity (e.g., trained public health staff and resources) to address current and emerging genetic health issues
- ▲ A need to collect more data about genetics and health (e.g., genetic conditions, birth defects, genetic health services) to guide public health planning and system improvement
- ▲ A need to enhance public understanding of genetics and the impact of genetics on health, with significant community interest in learning about these topics
- ▲ A recognition on the part of health care providers and consumers that genetic concepts are not generally incorporated into routine health care practice and a desire for additional training and technical assistance resources to make this happen
- ▲ A need identified on the part of individuals with inherited conditions, particularly adults, for more comprehensive and coordinated primary care services
- ▲ A recognition that Oregon has a cadre of skilled genetics professionals and an array of quality genetic services (e.g., genetic counseling, genetic testing, newborn screening), but that there remain a number of barriers to accessing services, including lack of awareness about the services, cost and insurance reimbursement for services, lack of services outside of the metropolitan areas and cultural barriers
- ▲ A general desire to expand and enhance population-based services (e.g., newborn screening) to benefit larger segments of the population, as long as personal choice is not compromised
- ▲ An identified need to inform public policy makers about the implications of genetic advances and to continue efforts to address community concern about issues such as genetic privacy and discrimination
- ▲ A need to assure involvement of diverse stakeholders, including multicultural groups and consumers, in genetic public policy decisions

Structure of the plan:

Oregon's Strategic Plan for Genetics and Public Health includes the following components: mission (our purpose for being); vision (our view of an ideal world); broad-based goals (what we want to happen as a result of our efforts), strategies (how we will work toward our goals), strategic objectives (our priority areas of focus over the next 3-5 years), tactics (things that we will do to address our priority areas), partners and resources (people, agencies, etc. that we will work with to meet our goals and address our priorities), timeline (target dates for initiation of activities in particular areas), and outcomes that may be impacted by strategies (measurable outcomes that we can monitor to track progress towards our goals).

Specific details about activities and dates will be incorporated into a Genetics Program work plan. Some of the specifics will depend largely on available resources and funding. The strategic plan will provide direction as we seek out these resources. A detailed evaluation plan will also be developed.

The strategic plan is meant to be a fluid document, one that can and will change with new findings and new priorities. Comments and suggestions are always welcome as we strive to make this a living, working document.

Notes on language and wording:

Throughout the plan we strove to use language that is inclusive and positive. In general, we chose the term “inherited conditions”, rather than genetic conditions to reflect the broad scope of conditions that are either primarily or partially genetic in nature. As more is learned about the interrelationship of genetics and health, it becomes increasingly clear that most if not all health conditions have a genetic component. Birth defects, referring primarily to congenital anomalies, were included in the plan intentionally. In practice, the needs of individuals and families that are impacted by birth defects and genetic conditions are similar.

The term “genetic services” is used throughout the document. This term refers to clinical health services that focus on the genetic or inherited components of health and disease. Genetic services may either be “primary level” services, provided by a primary care provider such as a family physician, or “specialty” services provided by trained genetics professionals such as genetic counselors or medical geneticists. In general, the use of the term “genetic services” in the plan reflects the “specialty” level of service unless otherwise noted.

Individual health services refer to services that are provided in the context of personal health care and are directed at meeting the needs of a particular individual or family. Population-based services refer to services such as newborn screening that are carried out on a population level (e.g., all newborns).

For questions or comments, please contact us at:

The Genetics Program

(A joint program of the Oregon Department of Human Services, Office of Family Health and the Oregon Health & Science University, Child Development and Rehabilitation Center)

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Glossary of Abbreviations and Acronyms

ASTHO- Association of State and Territorial Health Officials

ACGPR- Advisory Committee on Genetic Privacy and Research (statutory committee formed in 2001 to advise legislature on genetic policy issues)

CDC- Centers for Disease Control and Prevention (federal agency)

DHS/HS- Oregon Department of Human Services/Health Services (formerly Oregon Health Division)

DHS/HS/OFH- Office of Family Health (Oregon's state Title V agency)

HRSA- Health Resources and Services Administration (federal agency within the U.S. Department of Health and Human Services)

OHSU/CDRC- Oregon Health & Science University/Child Development and Rehabilitation Center (Oregon's Title V agency for children with special health needs)

Oregon's Strategic Plan for Genetics and Public Health

Mission

To improve the health and well-being of people living in Oregon who are impacted by inherited conditions and birth defects

Vision

We envision a world where genetics is viewed as an integral component of health and health care, where human genetic variation is celebrated, and where all people benefit from advances in genetic science and technology while privacy and personal choice are maintained.

Goals

- I. Reduce morbidity and mortality from inherited conditions and birth defects
- II. Improve quality of life for individuals and families impacted by inherited conditions and birth defects
- III. Empower people to make informed decisions about genetics and health

Strategies

I. Build public health infrastructure needed to address current and emerging issues in genetics and health

- a. Increase state genetics program capacity and ensure sustainability
- b. Ensure that state genetics program content is up-to-date and consistent with national, state and community priorities
- c. Enhance genetics content and competency of other public health programs and services

II. Improve availability and quality of data about inherited conditions, birth defects, and genetic services for public health planning and system improvement

- a. Increase availability of accurate, up-to-date information about incidence, prevalence and health outcomes for inherited conditions and birth defects
- b. Increase availability of information about utilization, access and quality of genetic services

III. Educate the public about genetics and health

- a. Increase public awareness of genetic services and resources in Oregon
- b. Increase public understanding of basic genetic principles and health issues, including ethical, legal and social implications of genetic advances
- c. Increase public awareness and practice of healthy behaviors to reduce risk of birth defects

IV. Promote integration of genetics into health care practice

- a. Increase health care provider understanding of genetic concepts and how they relate to health and health care
- b. Strengthen primary care provider capacity to provide “primary level genetic services” across the lifespan
- c. Increase health care provider promotion of healthy behaviors to reduce risk of birth defects
- d. Increase health care provider awareness and use of genetic services and resources

V. Improve availability and access to individual and population-based genetic services

- a. Increase insurance coverage and reimbursement for genetic services and supports
- b. Increase availability of genetic services outside of the Portland metro area
- c. Decrease cultural barriers to genetic services
- d. Expand/enhance newborn screening services for inherited and congenital conditions that are amenable to early identification and intervention

VI. Promote the development of public policy that protects individual and family health and privacy while supporting advancements in genetic science and technology

- a. Increase policy maker understanding of the ethical, legal and social implications of genetics and genetic technology
- b. Address concerns about genetic privacy and discrimination
- c. Ensure diverse input into public policy decisions about genetics

Denotes priority objectives as identified by the Genetics Plan Advisory Council

I. Build public health infrastructure needed to address current and emerging issues in genetics and health

Strategic Objectives	Tactics	Partners/Resources
Increase the state genetics program capacity and ensure sustainability	Identify program staffing and resource needs	DHS/HS-Office of Family Health OHSU/CDRC
	Secure short and long term funding for program staff and activities	DHS/HS-Office of Family Health, Office of Medical Assistance Programs Federal partners (HRSA, CDC) Other funders (e.g., NW Health Foundation)
	Centralize educational information, resources and technical assistance within the state genetics program	DHS/HS-Office of Family Health OHSU/CDRC
	Develop and maintain an accessible genetics program website	DHS/HS-Office of Family Health OHSU/CDRC
	Market the genetics program and its resources to the general public, health care providers, and key public health and other state policy leaders	DHS/HS-Administration OHSU/CDRC-Administration
Ensure that the state genetics program content is up-to-date and consistent with national, state and community priorities	Convene an expert advisory body to guide program direction and provide input into policies	Consumers/family advocacy Genetic service providers Health professionals/systems Ethicists/academicians

	Create opportunities for public dialogue and input from diverse communities into program activities and decisions	Multicultural, faith, business, academic communities DHS/HS-Office of Multicultural Health Geneforum.org Pacific Institute for Ethics and Social Policy
	Monitor state and national genetics and health policy issues and activities and incorporate into genetics program planning and activities	Federal partners (ASTHO, CDC, HRSA)
	Develop an ongoing evaluation process for the state genetics program and the strategic plan	Genetics advisory committee
Enhance genetics content and competency of other public health programs and services	Create a cross-program work group to identify opportunities for incorporating genetics into existing programs and services	DHS/HS- maternal and child health, chronic disease prevention/ health promotion, environmental health programs OHSU/CDRC Local health departments
	Develop educational opportunities in genetics for state and local public health program staff	DHS/HS-Offices Local health departments

	<p>Assure that genetics program staff and genetics professionals participate in work groups or activities that address conditions or topics of public health concern</p> <ul style="list-style-type: none"> • Newborn hearing screening • Newborn metabolic screening • Birth Defects • Cardiovascular health • Asthma • Obesity • Diabetes • Cancer • Racial and Ethnic Health Disparities • Others 	<p>DHS/HS-Offices</p> <p>OHSU/CDRC</p> <p>Genetic service providers</p>
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Outcomes:

- Increase proportion of public health program staff who have attended a genetics educational event
- Identify and increase the proportion of public health program staff who demonstrate understanding of basic genetic principles and applicability to public health
- Increase the proportion of public health program materials that include genetics information

II. Improve availability and quality of data about inherited conditions, birth defects, and genetic services for public health planning and system improvement

Strategic Objectives	Tactics	Partners/Resources
<p>Increase availability of accurate, up-to-date information about incidence, prevalence and health outcomes for selected inherited conditions and birth defects</p>	<p>Participate in the development of a module within the consolidated child and family health information system (FamilyNET) that supports identification and follow-up of children with special health needs, including those with inherited conditions and birth defects</p>	<p>DHS/HS-Office of Family Health, Office of Disease Prevention and Epidemiology (Vital Statistics), Public Health Lab</p> <p>OHSU/CDRC (HRSA Community Integration Grant)</p> <p>Oregon Commission on Children and Families</p> <p>Oregon Dept of Education</p>
	<p>Link newborn metabolic and hearing screening data with birth certificates to improve case finding</p>	<p>DHS/HS-Office of Family Health, Office of Disease Prevention and Epidemiology (Vital Statistics), Public Health Lab</p>
	<p>Support efforts to improve the accuracy of information about inherited conditions and congenital anomalies that is collected on birth certificates</p>	<p>DHS/HS-Office of Disease Prevention and Epidemiology (Vital Statistics)</p> <p>Birthing facilities</p>
	<p>Support research studies to evaluate interventions and health outcomes for specific inherited conditions or birth defects</p>	<p>DHS/HS-Public Health Lab (Newborn Screening Program)</p> <p>OHSU/CDRC- Genetics and Birth Defects Clinics</p> <p>Other genetic service providers (Kaiser, Legacy, Providence)</p>

	Explore the development and implementation of a state birth defects surveillance system	DHS/HS-Office of Family Health (Genetics), Office of Disease Prevention and Epidemiology OHSU/CDRC March of Dimes Hospitals/birthing facilities Federal partners (HRSA, CDC)
	Determine feasibility/desirability of increasing genetic or family history information in existing disease registries and surveillance systems <ul style="list-style-type: none"> • Cancer Registry • Diabetes Surveillance • Asthma Surveillance 	DHS/HS-Office of Disease Prevention and Epidemiology (Chronic Disease)
	Develop and implement targeted data collection methodologies that are inclusive of people of color to help identify and mitigate disparities related to inherited conditions and birth defects	Office of Multicultural Health African American Health Coalition Other Community Partners
Increase availability of information about utilization, access and quality of genetic services	Use existing population surveys to obtain information about access to and utilization of genetic services <ul style="list-style-type: none"> • Pregnancy Risk Assess and Monitor System (PRAMS) • Oregon Healthy Teens Survey • Behavioral Risk Factor Surveillance System (BRFSS) 	DHS/HS- Office of Family Health; Office of Disease Prevention and Epidemiology

	Explore the feasibility of standardized collection of core genetic services data from Oregon providers	Genetic service providers
	Conduct surveys or other activities to further delineate health care provider practices related to genetics	OHSU (Genetics Dept - S. Hayflick)

Outcomes:

- Identify incidence and prevalence of common birth defects/congenital anomalies (e.g., neural tube defects, cleft lip/palate, Down syndrome, congenital hearing loss) and document disparities
- Identify referral and utilization patterns for various genetic services and document disparities (e.g., multiple marker screening for pregnant women, prenatal cystic fibrosis carrier screening, genetic evaluation for congenital hearing loss)

III. Educate the public about genetics and health

Strategic Objectives	Tactics	Partners/Resources
Increase public awareness of genetic services and resources in Oregon (high priority)	Create and disseminate materials about how to access Oregon genetic services and other genetics-related resources	OHSU/CDRC Pacific Northwest Regional Genetics Group (PacNoRGG) Genetic service providers Support groups
	Create and disseminate consumer-oriented information about Oregon's Genetic Privacy Act	Advisory Committee on Genetic Privacy and Research
Increase public understanding of basic genetic principles and health issues, including ethical, legal and social implications of genetic advances	Advocate for enhancements to the state K-12 science and health benchmarks and curriculum related to genetics	Oregon Dept. of Education Schools of Education (teacher training)
	Improve quantity and accuracy of genetics information published in Oregon-based media	Newspapers (Oregonian, Eugene Register Guard, Salem Statesman) TV/Radio (Oregon Public Broadcasting and others)
	Identify opportunities to bring genetics-related information to interested community groups (e.g., incorporating genetics information into presentations about health topics that are relevant to a particular community or population)	Key informant interview contacts Multicultural communities Faith community Business community

Increase public awareness and practice of healthy behaviors to reduce risk of birth defects	Participate in the development of a social marketing campaign to increase use of multivitamins with folic acid by women of reproductive age	March of Dimes DHS-Folic Acid Committee (Perinatal and Child Health, Adolescent Health, Women's and Reproductive Health, WIC)
	Create (or) compile and disseminate educational materials related to birth defects prevention and avoidance of known teratogens	March of Dimes National Birth Defects Prevention Network CDC Center for Birth Defects and Developmental Disability

Outcomes:

- Identify and increase the proportion of K-12 students having coursework in genetics that covers basic principles as well as ethical, legal and social implications of genetic advances
- Identify and increase the proportion of K-12 students who demonstrate understanding of basic genetic principles
- Increase the proportion of pregnancies initiated with optimal folic acid use
- Decrease the incidence of neural tube defects (e.g., spina bifida)

IV. Promote integration of genetics into Oregon health care practice

Strategic Objectives	Tactics	Partners/Resources
<p>Increase health care provider understanding of genetic concepts and how they relate to health and health care (high priority)</p>	<p>Advocate for the addition or enhancement of case-based, experiential genetics content in Oregon health professional training programs, including:</p> <ul style="list-style-type: none"> • Nursing • Allied Health • Mental Health/Social Work • Public Health • Medicine 	<p>Public Health Training Programs (OHSU, PSU, OSU)</p> <p>Nursing Schools (OHSU, Univ. of Portland, Linfield College)</p> <p>Allied Health Training Programs (OT, PT, Speech, Audiology, PA)</p> <p>Social Work/Mental Health Training Programs</p> <p>Medical Training Programs (OHSU)</p>
	<p>Incorporate practical genetics education into existing continuing health professional education activities (or) develop new continuing education programs</p>	<p>Professional medical organizations (Oregon Academy of Family Physicians, Oregon Pediatric Society, American College of Obstetrics and Gynecology-Oregon chapter, Oregon Nurses Association, mental health professionals, others)</p>
	<p>Create and disseminate informational materials for health care providers about implementation of Oregon's Genetic Privacy Act</p>	<p>Advisory Committee on Genetic Privacy and Research</p>

<p>Strengthen primary care provider capacity to provide “primary level genetic services” across the lifespan</p>	<p>Disseminate professional standards and guidelines to primary care providers</p> <ul style="list-style-type: none"> • General standards and guidelines for incorporating genetics into primary care (e.g., taking family history, identifying and evaluating risk) • Guidelines for management of specific diseases or conditions across the lifespan (e.g., managing an adult with Down syndrome, a pregnant woman with PKU) 	<p>National professional organizations (American College of Medical Genetics, American Academy of Pediatrics)</p> <p>Genetic service providers</p>
	<p>Develop or create links to tools (e.g., web-based) for primary care providers to have timely access to accurate information about diagnosis and management of specific inherited conditions or genetic risks</p>	<p>GeneReviews web page</p> <p>Genetic service providers</p>
	<p>Support the development of ongoing technical assistance/ mentorship to primary care providers by genetic service providers (e.g., consider development of a provider hotline)</p>	<p>Genetic service providers</p>
<p>Increase health care provider promotion of healthy behaviors to reduce risk of birth defects</p>	<p>Participate in the development of an educational campaign to increase health care provider promotion of multivitamins with folic acid for all women of reproductive age</p>	<p>March of Dimes</p> <p>DHS/HS-Folic Acid Committee</p>

	Participate in the development of an educational campaign to increase health care provider recognition and early intervention for alcohol and other drug use during pregnancy	DHS/HS-Office of Family Health; Office of Mental Health and Addiction Services Northwest Indian Tribes Health professional organizations March of Dimes
Increase health care provider awareness and use of genetic services and resources	Create opportunities for networking between health care providers and genetic services providers	Genetic service providers Health professional organizations
	Create and disseminate informational materials targeted at health care providers about accessing genetic services in Oregon	PacNoRGG Genetic service providers

Outcomes:

- Increase proportion of health professional training programs that include genetics throughout training curriculum
- Increase proportion of physicians who have received specific training in the use and interpretation of genetic tests
- Increase proportion of physicians who routinely complete a comprehensive three-generation family history with their patients
- Increase proportion of individuals, especially adults, who have special needs due to inherited or congenital conditions who have a “medical home” (comprehensive, coordinated primary care)
- Increase proportion of primary care providers who routinely recommend multivitamins with folic acid to all women of reproductive age
- Increase proportion of primary care and prenatal care providers who routinely ask women about alcohol use and provide education about the effects of alcohol on pregnancy outcomes
- Increase the frequency of medically indicated referrals to genetic specialty services

V. Improve availability and access to individual and population-based genetic health services

Strategic Objectives	Tactics	Partners/Resources
Increase insurance coverage and reimbursement for genetic services and supports (high priority)	Develop educational presentations for health plan administrators about the role and value of genetic services in prevention and health promotion	DHS/HS-Office of Medical Assistance Programs Health plans/insurers
	Advocate for health plan quality assurance and improvement measures related to genetic services (primary and specialty level services) as an incentive to assure service coverage	Health plans/insurers
	Identify and support genetic service provider billing practices that optimize reimbursement	American College of Medical Genetics resources Genetic service providers Health plans
	Identify and secure funding for genetic services for uninsured and underinsured <ul style="list-style-type: none"> • Multiple marker screening during pregnancy 	DHS/HS-Office of Medical Assistance Programs
	Explore feasibility & desirability of promoting legislation to mandate: licensure of genetic counselors and insurance reimbursement for genetic counseling	Genetic service providers Health plans Dept of Consumer and Business Affairs (Insurance Division)
Increase availability of genetic services outside of the Portland metro area (high priority)	Develop and implement plan for delivering genetic services in rural and outlying areas using nontraditional methods (e.g., telemedicine)	Oregon Health & Science University Other genetic service providers

	Support the development of ongoing technical assistance/ mentorship from genetic service providers in Portland to health care providers in rural areas	Genetic service providers Primary care professional organizations (family medicine, internal medicine, pediatrics, obstetrics)
Decrease cultural barriers to genetic services (high priority)	Create and disseminate culturally sensitive educational materials about genetic health services, including development of materials in multiple languages	HRSA-Tandem Mass Spectrometry: Financial, Ethical, Legal, Social Issues SPRANS grant partners (HI, ID, WA, CA, AK)
	Create educational opportunities for genetic service providers and other health providers to learn about cultural issues that impact perceptions about genetics and health practices	DHS/HS-Office of Multicultural Health Genetic service providers Health professional organizations Multicultural community groups
	Create educational opportunities for medical interpreters to improve their skills related to genetic service visits	Medical interpreters Genetic service providers
Expand/enhance newborn screening services for inherited and congenital conditions that are amenable to early identification and intervention	Implement tandem mass spectrometry technology and screening protocols for Medium Chain Acyl CoA-Dehydrogenase Deficiency (MCADD) and other inherited metabolic disorders	DHS/HS-Public Health Lab (Newborn Screening Program)
	Update endocrine testing technology to screen for congenital hypothyroidism and congenital adrenal hyperplasia	DHS/HS-Public Health Lab (Newborn Screening Program)

	Convene newborn metabolic screening program advisory body to provide guidance on policies such as selection of additional conditions for screening	DHS/HS-Public Health Lab (Newborn Screening Program)
	Create and disseminate culturally competent information about expanded newborn screening services to health care providers and expectant/new parents	DHS/HS-Public Health Lab (Newborn Screening Program) HRSA Tandem Mass Spectrometry: SPRANS Grant Prenatal care providers/ birthing facilities

Outcomes:

- Increase proportion of health plans that cover genetic services for at-risk individuals and their family members
- Increase proportion of genetic service claims that are reimbursed at fair market value
- Increase proportion of uninsured/underinsured individuals who receive medically indicated genetic services (e.g., multiple marker screening, genetic counseling for undocumented pregnant women)
- Increase proportion of state population with access to genetic services within 50 miles
- Increase proportion of medical interpreters who have received basic genetics education
- Increase proportion of expectant/new parents who are aware of the newborn metabolic screening program purpose and process
- Increase the number of children with Medium Chain Acyl CoA-Dehydrogenase Deficiency (MCADD) who are identified within the first two weeks of life
- Increase the number of children with Congenital Adrenal Hyperplasia (CAH) are identified within the first two weeks of life

VI. Promote the development of public policy that protects individual and family health and privacy while supporting advancements in genetics science and technology

Strategic Objectives	Tactics	Partners/Resources
Increase policy maker understanding of the ethical, legal and social implications of genetics and genetic technology (high priority)	Develop educational materials and presentations for legislators, their staffs, and other policy makers about the policy implications of advances in genetics	DHS/HS-Legislative affairs Legislators Advisory Committee on Genetic Privacy and Research
Address concerns about genetic privacy and discrimination	Convene and facilitate state Advisory Committee on Genetic Privacy and Research (ACGPR)	ACGPR committee members: <ul style="list-style-type: none"> • Consumers • Biotechnology/ pharmaceutical industry • Academic/Research institutions • Health professionals/ clinicians • Bioethics • American Civil Liberties Union (ACLU)
	Promulgate and implement administrative rules corresponding to Oregon Genetic Privacy Act	ACGPR committee members
	Create opportunities for public dialogue and input into public policy decisions related to genetic privacy and discrimination issues	ACGPR committee members Geneforum.org (public opinion survey)

	<p>Study and develop policy recommendations related to:</p> <ul style="list-style-type: none"> • Genetic discrimination in insurance and employment settings • Adoption issues (privacy of genetic information about biological parents) • Reproductive technologies (privacy of genetic information about egg and sperm donors) 	ACGPR committee members
Ensure diverse input into public policy decisions about genetics	Maintain advisory bodies that represent the cultural, professional, geographic, gender and age diversity of the state	Advisory Committees (ACGPR, Newborn Screening Advisory Committee, Genetics Advisory Committee)
	Develop an ongoing review process to assure that opportunities for public input are accessible to individuals from diverse backgrounds	DHS/HS-Office of Multicultural Health

Outcomes:

- Identify and decrease occurrence of violations of state genetic privacy rules and regulations
- Increase proportion of Oregon legislators who have participated in an educational session on genetics and public policy

Next Steps:

Completion of Oregon's Strategic Plan for Genetics and Public Health is an important step, but only one step, towards improving the health and well-being of those in Oregon who are impacted by inherited conditions and birth defects either personally, in their families, or in their communities. In order to make a difference, we must turn "plans" into "action". Over the next months, the State Genetics Program and its partners will:

- Share the plan and its vision widely with state leaders in health and public policy, garnering support and new insights.
- Identify and secure the resources needed to carry out the plan activities.
- Develop tools to measure, monitor and report our progress toward plan objectives.
- Remain alert to evolving science, technology and policy issues and incorporate into ongoing planning.
- Reach out to Oregon's diverse communities to assure that the voices of those we wish to serve are heard.

We hope you will join us in this exciting opportunity!

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- The Genetics Steering Committee & Genetics Plan Advisory Council;
- Oregon's genetic service providers (e.g., geneticists, genetic counselors, laboratory professionals);
- Colleagues from other state genetic programs; and
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