

Oklahoma State Genetics Plan

Executive Summary

The *State Genetics Plan* was a collaborative effort between the Oklahoma State Department of Health (OSDH) and the Oklahoma Genetics Advisory Council (OGAC) and its committees. Funding for the project was provided by a federal grant from the Maternal Child Health Bureau, Health Resources and Services Administration (HRSA). Numerous public health documents and Web sites were reviewed to assist in the development of a comprehensive plan including the U.S. Department of Health and Human Services *Healthy People 2010* initiative, the Maternal and Child Health Bureau *All Aboard the 2010 Express: a 10 Year Action Plan for Children with Special Health Care Needs and Their Families*, Centers for Disease Control (CDC) Genetics and Disease Prevention, Council of Regional Networks for Genetic Services (CORN), Human Genome Project, and the American Academy of Pediatrics. The 2001 statewide genetics needs assessment also provided guidance for development. Public comment was sought through posting the action plan on the Oklahoma State Department of Health Web site and comments were requested through a mailing to Family Voices subscribers and to other public health genetic programs throughout the United States. This comprehensive document provides policymakers and genetic stakeholders an overview of the history and current directions of genetic medicine, the local and national legislation on genetic discrimination, and a review of the important role public health must play in this exciting field of medicine and health.

Advances in genetics through the Human Genome Project challenge the traditional medical model. The anticipated paradigm shift from illness care to preventive medicine interfaces with public health's long history in health promotion and disease prevention. The Human Genome Project is the science that is thrusting public health into the molecular age of health maintenance. A public health genetics program soon will be as important in disease prevention as immunization programs are today. However, scientific advances come with tough ethical, legal, and social issues. Concerns about insurance and employee discrimination based on genetic testing have been documented and must be monitored and addressed to ensure Oklahomans benefit from genetic medicine without discrimination or exploitation occurring or fear that they will occur. The establishment of a sustainable public health infrastructure to plan, implement, monitor, and evaluate genetics will be key to ensuring Oklahoman's benefit from the advances emanating from the Human Genome Project. The *State Genetics Plan* is a five-year action plan with the following mission and goals:

Mission Effective public health strategies will ensure access to quality and timely genetic information, screening, education, and family-centered comprehensive services.

Goal 1 Educate providers, policymakers, insurance providers, medical/health career students, the public, affected families, and university and high school students regarding genomics, local genetic resources, genetic services (availability, access, indications, and benefit) and the process of referring for genetic services.

Goal 2 Develop and maintain a responsive public health genetics program to plan, implement, monitor, and evaluate genetics education and services in Oklahoma.

Goal 3 Maximize the quality of genetic testing and the effectiveness of public health screening programs to serve all the citizens of Oklahoma.

Implementation of the *State Genetics Plan* will enhance the capacity of the public health genetics programs to meet the needs of Oklahomans. For more information or comments, please contact the State Genetics Coordinator at (405) 271-6617. For information about local genetic clinical and public health program services and resources, visit the OSDH genetics Web site at <http://www.health.state.ok.us/program/gp>.