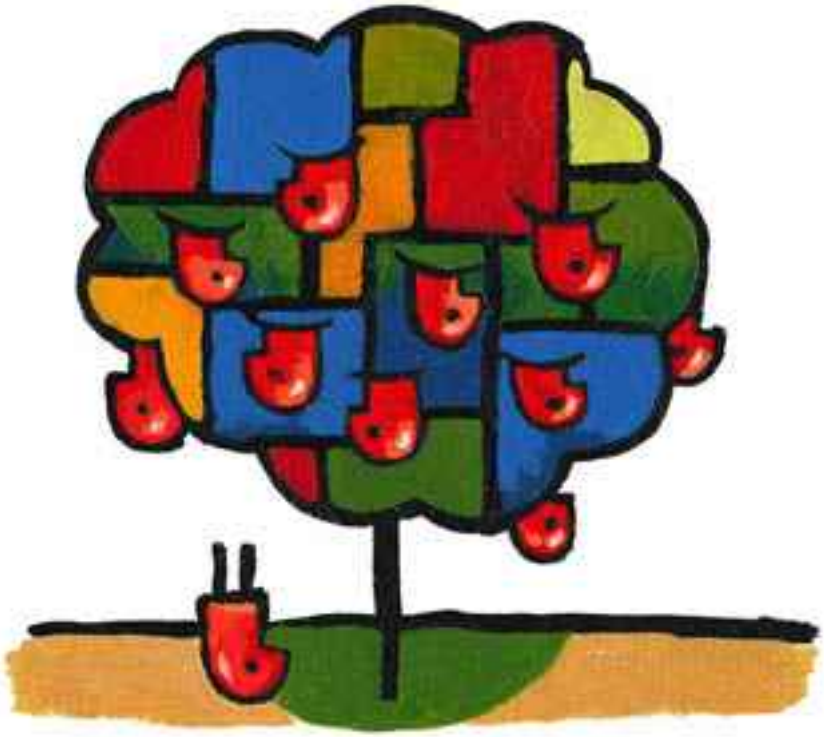

Goal 3 Action Plan

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

Objective 1 - The OSDH will maintain and develop an adequate public health infrastructure to administer a comprehensive public health newborn screening program that is coordinated and integrated into the health care delivery system.

Action Steps (◇ symbol identifies prioritized action steps):

◇ Establish a comprehensive newborn screening follow-up program utilizing the national guidelines from the AAP, CORN, *2010 Express* and recommendations from the National Newborn Screening and Genetics Resource Center's (NNSGRC) site visit conducted in March 2001 to include (priority number 1):

- i. Quality assurance (evaluation) program for the newborn metabolic screening program
- ii. Integration with newborn hearing program
- iii. Maintenance of short-term follow-up services
- iv. Long-term follow-up services
- v. Adult transition services
- vi. Development of a birth certificate matching system to ensure all infants are screened for the disorders and hearing loss.
- vii. Establishment of hospital profiles (a report on specimen submission)
- viii. Review policy on storage and use of filter paper specimens
- ix. Development of educational materials that are culturally sensitive and available in different languages.

◇ Maintain and collaborate with the Newborn Screening Programs and Pediatrics Committee of OGAC (priority number 2):

- i. Develop a strategic plan to address the issue of insurance coverage for medical foods (low-phenylalanine formula and low protein food) issues for children and adults affected by PKU.
- ii. Monitor and assess new technologies for newborn screening.
- iii. Review and make recommendations annually through quality assurance reports for the newborn metabolic screening program.

iv. Address issues of access to newborn screening records for both short-term records of newborns with abnormal results and long-term follow-up of diagnosed cases, including possible access of this information via web by primary care providers (medical home).

◇ In collaboration with the OSDH leadership, Screening and Special Services Newborn Screening Program, Public Health Laboratory Service, and the Newborn Screening Programs and Pediatrics Committee of OGAC, review and develop strategies for implementation of recommendations from the National Newborn Screening and Genetics Resource Center's (NNSGRC) site visit conducted in March 2001 with priority issues of (priority number 3):

i. Adequate program funding
ii. Administrative structure
iii. Adequate staff for short-term and long-term follow-up

○ Facilitate the appropriate integration of new genetic technologies into health care and public health activities i.e., expanded newborn screening for rare metabolic disorders:

i. As recommended by OGAC, continue to promote the expansion of newborn screening to include cystic fibrosis (CF), congenital adrenal hyperplasia (CAH), and MCAD testing and collaborate with stakeholders to achieve funding for expansion of services.
ii. Collaborate with the public health laboratory system to ensure new technology for mass screening is monitored, evaluated, and implemented in accordance with the State Board of Health Policy on Newborn Metabolic Disorder Screening Program.

○ Collaborate with the OUHSC to recruit a M.D./D.O. metabolic specialist to Oklahoma.

Objective 2 - The OSDH Genetics Program, in collaboration with the Adult Committee and the Birth Defects Registry, Prenatal Screening and Diagnosis Committee of OGAC, will monitor and assess new technologies for screening in the prenatal and adult population for genetic disorders.

Action Steps:

○ Monitor new technologies and possible uses for population (preconception, prenatal, and adult) screening.

○ Promote and facilitate breast cancer hereditary risk assessment for all women by encouraging prenatal providers, family practice providers, and mammography centers to incorporate a genetic risk assessment questionnaire to be administered during routine breast examination or mammogram visit, and refer those women identified at risk for genetic counseling and possible susceptibility genetic testing.

Objective 3 - The OSDH Genetics Program, in collaboration with the OGAC and its committees, will maximize appropriate access to quality genetic testing.

Action Steps (◇ symbol identifies prioritized action steps):

◇ In collaboration with the Public Health Policy Committee of OGAC, meet with local genetic laboratories to address the issue of reimbursement for genetic testing and develop strategies to improve reimbursement (priority number 4).

◇ In collaboration with the Public Health Policy Committee of OGAC, develop recommendations (standards) for (priority number 5):

i. quality genetic laboratory services
ii. informed consent, including newborn screening
iii. indications for genetic counseling
iv. patients rights related to genetic testing

○ In collaboration with the Evaluation Committee of OGAC, establish a system at the OSDH to monitor availability, quality, utilization, and accessibility of genetic testing for all Oklahomans.