



Genetics Program

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Oklahoma Genetics Advisory Council

Organizational Goals and Structure

MISSION STATEMENT

To prevent morbidity and mortality among individuals and families with or at risk of genetic, congenital, and/or familial disorders by assuring that all Oklahomans have access to quality screening, education and family-centered comprehensive services.

GOAL

To advise the Commissioner of Health regarding public health measures to achieve the mission.

Issues to be Addressed

- Assure access to genetic services.
- Provide public health leadership in genetics.
- Assess needs.
- Promote partnerships and coordination between genetic stakeholders at the state and national level.
- Address ethical, legal and social issues including confidentiality and discrimination.
- Advocate for policies to ensure provision of comprehensive integrated genetic services.
- Monitor and improve the use of data systems related to genetics and congenital disorders.
- Promote efforts to increase professional and public awareness through education.
- Review, incorporate and promote advances in genetic technology.
- Communicate and disseminate information on emerging genetic issues.
- Explore and advocate for methods of reimbursement for genetic services.

STRUCTURE

The Commissioner of Health shall appoint Oklahoma Genetics Advisory Council (OGAC) members and designate an interim chairperson until such a time an election can be held. Oklahoma State Department of Health (OSDH) personnel shall staff the committee. The committee shall meet a minimum of three times a year. Standing rules of operation will be established to conduct committee activities.

MEMBERSHIP

The OGAC should be formed of 20 to 28 members with representation from the following disciplines and interested parties: clinical genetic service providers, laboratory genetic service

providers, primary care providers, maternal fetal medicine providers, oncologist, ethicist, medical reimbursement representation, academic medical representation, consumers and families affected by a genetic disorder, community representation, and others who are involved in the administration or direct provision of services for families with genetic or congenital disorders. Attention will be given to ensure OGAC members represent the state's ethnic diversity. There will be 10 to 20 ex-officio members from OSDH and Department of Human Services representing the following areas: Legal, Genetics, Birth Defects Registry, Newborn Metabolic Disorder Screening, Women's Health, Early Intervention, Assessment and Epidemiology, Chronic Disease, Minority Health, and Children with Special Health Care Needs.

Standing committees of OGAC will be established to address specific issues. A membership of 8 to 15 will include member(s) from the OGAC and other individuals with specific expertise that will assist the committee. The committees will meet as often as necessary for task completion. Standing committees will be established and include, but not limited to, Public Health Policy, Birth Defects Registry, Prenatal Screening and Diagnosis, Newborn Screening Programs and Pediatrics, Education, Evaluation, Adult Genetics, and Family Advisory.

Council Member Representation:

Clinical Genetic & Laboratory Service Providers:

- OU College of Medicine
- Chapman Institute of Medical Genetics
- Other Medical Geneticists
- Genetic Counselor
- Genetic Laboratory Service Provider

Primary Care Providers:

- Pediatrics (AAP)
- OB-GYN (ACOG)
- Family Practice
- Oklahoma Osteopathic Association

Other:

- Maternal Fetal Medicine Provider
- Metabolic Specialist
- Adult Oncologist
- Pediatric Hematologist/Oncologist
- Ethicist
- Insurance Commissioner
- Oklahoma Health Care Authority
- College of Public Health
- Indian Health Representatives
- Consumers/Families Affected by a Genetic Disorder
- Community Representatives
- Clergy
- Hospital Association

Ex-Officio Member Representation:

Oklahoma State Department of Health Programs or Positions to be represented:

- State Epidemiologist
- Legal Division
- Maternal and Child Health Service
- Genetics
- Birth Defects Registry
- Newborn Metabolic Disorder Screening
- Women's Health
- Early Intervention
- Assessment and Epidemiology
- Chronic Disease
- Minority Health
- Title V Parent Advocate

Department of Human Services Programs to be represented:

- Children with Special Health Care Needs

OGAC Standing Committees and Issue Assignments

Adult Genetics

- Provide recommendations for pre-symptomatic testing of adult onset genetic disorders such as breast and colon cancer, and mental health.
- Assess and provide recommendations for the provision of services for adults with pediatric onset genetic disorders.

Birth Defects Registry, Prenatal Screening and Diagnosis

- Develop procedures that address the request of Birth Defects Registry data by “outside” investigators for the use in research.
- Provide recommendations on how to inform women, who have had a pregnancy with a neural tube defect (NTD), on the use of folic acid supplementation for future pregnancies.
- Provide recommendation on how the data of the Birth Defects Registry can be used to better serve the public.
- Develop criteria for the investigations of clusters of birth defects identified in the state.
- Assess and provide recommendations on the use of MSAFP and ultrasound screening.

Evaluation

- Develop evaluation measures to monitor data and data collection quality.
- Provide recommendations for identifying the components of Oklahoma’s genetics programs and activities.
- Quality assurance of genetic services.
- Provide recommendations for epidemiological use data.
- Provide recommendations for utilization of data for research needs/opportunities.

Family Advisory Committee

- Family to Family Support
- Barriers to care

Genetics Education Committee of Oklahoma (GECO)

- Provide recommendations on the provision of formal clinical genetic education to the various institutions of learning, i.e., medical schools, nursing schools.
- Write and approve a genetic service directory for the State of Oklahoma.
- Provide recommendations regarding public awareness campaigns and health professional education.
- Provide recommendations and promote the utilization of various educational tools, i.e., interactive video, pamphlets, e-mail, and web site.
- Provide recommendations to ensure access and integration of genetic services into established systems of care.

Newborn Screening Programs and Pediatrics

- Review and provide recommendations for revisions to the NMDSP Rules and Regulations as requested.

- Provide recommendations as requested on the addition of new tests to the screening battery.
- Provide consultation on issues related to newborn screening programs as requested.

Public Health Policy

- Review and report legislation related to genetics.
- Provide recommendation on legislative issues related to birth defects and genetic disorders, i.e., genetic discrimination.
- Provide recommendations on policy and service needs.
- Collaborate with local, regional and national entities regarding activities on policy development related to genetics and public health.
- Provide recommendations for assessing population needs.
- Review and provide recommendations for clinical services statewide and address the special needs of rural communities (including the use of interactive video throughout the state).