

Rules of
Department of Health
Division 40—Division of Maternal, Child and
Family Health
Chapter 8—Missouri Genetics Disease Program

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**Title 19—DEPARTMENT OF
HEALTH**

**Division 40—Division of Maternal, Child
and Family Health**

**Chapter 8—Missouri Genetics Disease
Program**

19 CSR 40-8.010 Definitions

PURPOSE: This rule defines the terms used in this chapter.

(1) The “Missouri Genetics Disease Program” is the program of the Department of Health authorized by the provisions of statute sections 191.300 to 191.331, 191.340, and 191.365 to 191.380, RSMo.

(2) “Department” is the Missouri Department of Health.

(3) “Tertiary genetic centers” means the permanent genetic divisions in university medical schools that provide comprehensive genetic diagnostic, treatment and counseling services.

(4) “Outreach clinics” are the medical clinics which provide genetic diagnosis and counseling at sites away from the tertiary genetic centers.

(5) “Genetic counseling” is the provision and interpretation of medical information based on expanding knowledge of human genetics.

(6) “Genetic disorders” are those abnormalities of structure, function, or body metabolism which may be inherited or may result from damage to the fetus.

(7) “Genetic screening” refers to the search through testing for persons with genetic disorders.

AUTHORITY: section 191.315, RSMo Supp. 1997. Original rule filed Oct. 6, 1998, effective May 30, 1999.*

**Original authority 1985, amended 1993, 1995.*

**19 CSR 40-8.020 Tertiary Genetic Center
Responsibilities**

PURPOSE: The Department of Health administers the Missouri Genetics Disease Program to provide genetic diagnostic and counseling services. The department may contract with qualifying tertiary genetic centers to provide genetic services for residents of Missouri. This rule sets forth the requirements for becoming a contractor and the

reimbursement criteria to receive funding for tertiary genetic centers awarded contracts pursuant to this program.

(1) The requirements for a tertiary genetic center to participate in the Missouri Genetics Disease Program are that the center—

(A) Maintains staff, facilities, resources and equipment which have the capability to provide up-to-date and comprehensive genetic services;

(B) Staff must have clinical expertise in syndrome identification. The center must provide a minimum of two (2) personnel, one (1) of which shall be a medical geneticist and the other shall be a genetic associate. The center’s staff shall additionally include a nurse, a social worker, a cytogeneticist, a psychologist, and clerical staff;

(C) Provide existing access to the following specialists: audiologist, ear, nose and throat specialist, pediatric neurologist, pediatric cardiologist, orthopedic specialist, neonatologist, perinatologist, and prenatal ultrasonography specialist;

(D) Be capable of providing pedigree analyses, full diagnosis, referral for patient evaluation and lab work, and multidisciplinary consultation; and

(E) Be equipped with a cytogenetic laboratory, a biochemical genetics laboratory, and a cell culture laboratory with full diagnostic capabilities. If the center has only one (1) laboratory, it must have all of the above described specific laboratory capabilities.

(2) Tertiary genetic centers under contract with the Department of Health, pursuant to the Missouri Genetics Disease Program, must satisfy the following criteria in order to receive reimbursement:

(A) Perform service community networking which establishes and maintains appropriate and effective coordination with other related health services and genetic disease-related programs in the area. To facilitate and carry out contractual activities, the contractor shall permit expansion of less-developed programs to strengthen limited activities and develop new programs in an area in which no current program exists, for example, establishment of a teratogen hotline;

(B) Provide genetic evaluations for individuals and their families who are at risk for genetic or genetic-related conditions;

(C) Provide genetic counseling and upon completion of the diagnosis give a complete explanation of the findings to the individual and their family;

(D) Conduct genetic outreach activities; the delivery of genetic diagnosis, counseling,

and education services at outreach clinic sites;

(E) Provide professional education programs for physicians, nurses, scientists, technicians, therapists, and other allied health professionals regarding the causes, methods of treatment, prevention and cure of genetic diseases;

(F) Provide educational activities to the general public regarding the various types of genetic disorders and their modes of inheritance; the impact of genetic disorders in Missouri; and genetic services that are available in Missouri; and

(G) Collect demographic and other patient data as identified by the Missouri Genetics Disease Program and report information according to current reporting requirements established through the Genetic Automated Office System (GOAS).

AUTHORITY: section 191.315, RSMo Supp. 1997. Original rule filed Oct. 6, 1998, effective May 30, 1999.

**Original authority 1985, amended 1993, 1995.*