

§1533. Advisory program for genetic conditions

1. Purpose; program. A voluntary statewide genetics program is established, which offers testing, counseling and education to parents and prospective parents. The program shall include, but not be limited to, the following services:

- A. Follow-up programs for newborn testing, with emphasis on the counseling and education of women at risk for maternal phenylketonuria (PKU); [PL 1983, c. 848, §2 (NEW).]
- B. Comprehensive genetic services to all areas of the State and all segments of the population; [PL 1983, c. 848, §2 (NEW).]
- C. Development of counseling and testing programs for the diagnosis and management of genetic conditions and metabolic disorders; and [PL 1983, c. 848, §2 (NEW).]
- D. Development and expansion of educational programs for physicians, allied health professionals and the public, with respect to:
 - (1) The nature of genetic processes;
 - (2) The inheritance patterns of genetic conditions; and
 - (3) The means, methods and facilities available to diagnose, counsel and treat genetic conditions and metabolic disorders. [PL 1983, c. 848, §2 (NEW).]

[PL 1983, c. 848, §2 (NEW).]

2. Responsibility for the program. The commissioner shall designate personnel within the department's division of family health to:

- A. Coordinate matters pertaining to detection, prevention and treatment of genetic conditions and metabolic disorders; [PL 1983, c. 848, §2 (NEW).]
 - A-1. Establish, maintain and operate a tracking system to assess and coordinate treatment related to congenital, genetic and metabolic disorders; [PL 2009, c. 514, §3 (NEW).]
 - A-2. Evaluate the effectiveness of screening, counseling and health care services in reducing the morbidity and mortality caused by heritable disorders in newborns and children; [PL 2009, c. 514, §3 (NEW).]
 - A-3. Collect, analyze and make available to families data on certain heritable disorders; [PL 2009, c. 514, §3 (NEW).]
 - A-4. Ensure access to treatment and other services that will improve clinical and developmental outcomes. To accomplish this, the department is authorized to share data with other states' public health newborn blood spot screening programs; [PL 2009, c. 514, §3 (NEW).]
- B. Cooperate with and stimulate public and private not-for-profit associations, agencies, corporations, institutions or other entities involved in developing and implementing eligible programs and activities designed to provide services for genetic conditions and metabolic disorders; [PL 1983, c. 848, §2 (NEW).]
- C. Administer any funds that are appropriated for the services and expenses of a genetic screening, counseling and education program; [PL 2009, c. 514, §3 (AMD).]
- D. Enter into agreements and contracts for the delivery of genetic services; [PL 1983, c. 848, §2 (NEW).]
- E. Establish, promote and maintain a public information program on genetic conditions and metabolic disorders and the availability of counseling and treatment services; [PL 1983, c. 848, §2 (NEW).]

F. Publish, from time to time, the results of any relevant research, investigation or survey conducted on genetic conditions and metabolic disorders and, from time to time, collate those publications for distribution to scientific organizations and qualified scientists and physicians; and [PL 1983, c. 848, §2 (NEW).]

G. Adopt rules necessary to carry out the purposes of this chapter. [PL 2009, c. 514, §3 (AMD).]
[PL 2009, c. 514, §3 (AMD).]

3. Eligibility for contracts. A public or private not-for-profit association, agency, corporation, institution or other entity shall be eligible to enter into contracts pursuant to this section if it satisfies the following requirements.

A. The entity shall submit an application for a contract in the manner and on forms prescribed by the commissioner. [PL 1983, c. 848, §2 (NEW).]

B. The project or activity to be carried out by the entity, either directly or through an integrated, coordinated arrangement, shall include some or all of the following services:

(1) Prenatal testing and diagnosis;

(2) Genetic diagnosis, treatment and counseling;

(3) Newborn metabolic testing, laboratory services and nutritional follow-up; or

(4) Genetics education programs for health professionals and the public. [PL 1983, c. 848, §2 (NEW).]

C. The project or activity shall be consistent with the objectives of this section and shall be coordinated with resources existing in the community in which it is located. [PL 1983, c. 848, §2 (NEW).]

[PL 1983, c. 848, §2 (NEW).]

SECTION HISTORY

PL 1983, c. 848, §2 (NEW). PL 2009, c. 514, §3 (AMD).

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