

42 U.S. Code § 300b-5

Sickle cell disease and other heritable blood disorders research, surveillance, prevention, and treatment

(a) Grants

(1) In general

The Secretary may award grants related to heritable blood disorders, including sickle cell disease, for one or more of the following purposes:

- (A) To collect and maintain data on such diseases and conditions, including subtypes as applicable, and their associated health outcomes and complications, including for the purpose of—
 - (i) improving national incidence and prevalence data;
 - (ii) identifying health disparities, including the geographic distribution, related to such diseases and conditions:
 - (iii) assessing the utilization of therapies and strategies to prevent complications; and
 - (iv) evaluating the effects of genetic, environmental, behavioral, and other risk factors that may affect such individuals.
- (B) To conduct public health activities with respect to such conditions, which may include—
 - (i) developing strategies to improve health outcomes and access to quality health care for the screening for, and treatment and management of, such diseases and conditions, including through public-private partnerships;
 - (ii) providing support to community-based organizations and State and local health departments in conducting education and training activities for patients, communities, and health care providers concerning such diseases and conditions;
 - (iii) supporting State health departments and regional laboratories, including through training, in testing to identify such diseases and conditions, including specific forms of sickle cell disease, in individuals of all ages; and
 - (iv) the identification and evaluation of best practices for treatment of such diseases and conditions, and prevention and management of their related complications.

(2) Population included

The Secretary shall, to the extent practicable, award grants under this subsection to eligible entities across the United States to improve data on the incidence and prevalence of heritable blood disorders, including sickle cell disease, and the geographic distribution of such diseases and conditions.

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