

NORTH CAROLINA GENERAL ASSEMBLY  
1973 SESSION

CHAPTER 570  
HOUSE BILL 32

AN ACT TO ESTABLISH A COUNCIL ON SICKLE CELL SYNDROME AND RELATED GENETIC DISORDERS AND TO AUTHORIZE THE STATE BOARD OF HEALTH TO ESTABLISH PROGRAMS FOR EDUCATION, TESTING AND COUNSELLING FOR SICKLE CELL SYNDROME AND RELATED GENETIC DISORDERS.

The General Assembly of North Carolina enacts:

**Section 1.** A Council on sickle cell syndrome shall be appointed by the Governor to determine the needs and to make recommendations for legislative action with regard to sickle cell syndrome and related genetic disorders.

**Sec. 2.** In making the appointments, due consideration should be given to persons representing the following areas;

- (1) Members of community foundations interested in sickle cell syndrome and related disorders;
- (2) Public Health Officials; Federal, State and local officials from offices concerned with rehabilitation and social services;
- (3) Faculty of Universities and Staff of Hospitals;
- (4) Members of Local and State School Boards;
- (5) Patients with, or relatives of patients with sickle cell disease.

**Sec. 3.** The Council shall consist of a temporary chairman appointed by the Governor and 14 other members. They shall serve without compensation except for reimbursement for travel and expenses in pursuit of the business of the Council.

**Sec. 4.** The Council shall be empowered to employ a staff and to obtain office space.

**Sec. 5.** The work-scope of the Council shall involve the following:

- (1) Assess the needs of the State with regard to:
  - a. Education of the people about sickle cell syndrome and related genetic disorders;
  - b. Personnel and facilities available for the treatment of patients with sickle cell syndrome and related genetic disorders;
  - c. Mechanisms for assisting in the payment of medical expenses incurred by sickle cell syndrome and related genetic disorders;
  - d. Rehabilitation of patients with sickle cell syndrome and related genetic disorders;
  - e. Discrimination against patients with sickle cell syndrome in employment, insurance and other activities;
  - f. Establishment of centers for testing for sickle cell syndrome and related genetic disorders;
  - g. Special education and counsel of those tested in such centers;
  - h. Research in the diagnosis and treatment of sickle cell syndrome and other related genetic disorders;
  - i. Critique of present organizations with interest in sickle cell disease.

- (2) The Council shall study programs currently active concerning sickle cell syndrome and related genetic disorders and shall make recommendations for legislation which would coordinate the currently active programs with those recommended in the "work-scope of the Council".
- (3) The Council shall consult with and advise the North Carolina State Board of Health regarding the establishment of programs for and the promulgation of rules and regulations governing education, voluntary testing and adequate counselling for sickle cell syndrome and related genetic disorders.
- (4) Upon completion of the study, the Council shall recommend to the Legislature such appropriate legislation as will best serve the needs of the people of North Carolina with regard to sickle cell syndrome and related genetic disorders.

**Sec. 6.** The North Carolina State Board of Health is hereby authorized, after consultation with the Council on sickle cell syndrome, to promulgate rules and regulations providing for the establishment and operation of programs providing education, voluntary testing, and adequate counselling for sickle cell syndrome and related genetic disorders. "Sickle cell syndrome" includes sickle cell disease, sickle cell trait, sickle cell thalassemia, and variants.

**Sec. 7.** The State Health Director is hereby authorized to initiate pilot programs for education, voluntary testing, and counselling for and about sickle cell syndrome and related genetic disorders.

**Sec. 8.** If any individual is found to have any aspect of the sickle cell syndrome or related genetic disorders, it shall be the duty of the local health department to inform the individual to that effect. It shall be the duty of the North Carolina State Board of Health to make available testing and counselling services to any persons so requesting testing relative to sickle cell syndrome or related genetic disorders, their characteristics, symptoms, traits, effects and treatments. Such testing and counselling by the North Carolina State Board of Health and local health departments shall be furnished without cost to persons requesting it.

**Sec. 9.** Any program for voluntary testing shall begin no sooner than 60 days after the implementation of an adequate and effective educational program. Counselling shall be done "only by persons adequately trained and certified according to criteria established by recognized authorities in the field of human genetics.

**Sec. 9 1/2.** Effective July 1, 1974, the Council is transferred to the Department of Human Resources, and the function of the Council shall be carried out by said Department in the same manner as provided in Section 9 and each subsection of the same as appears in Chapter 476 of the 1973 Session Laws, and the codifiers of the Statutes shall insert the appropriate General Statute Chapter and Section.

**Sec. 10.** This act shall become effective upon ratification.

In the General Assembly read three times and ratified, this the 17th day of May, 1973.