

APPROVED AND SIGNED BY THE GOVERNOR

Date 4-29-81

Time _____

No: 475

WEST VIRGINIA LEGISLATURE
REGULAR SESSION, 1981



ENROLLED

SENATE BILL NO. 475

(By Mrs. Spears & Mr. Shise)



PASSED April 11, 1981

In Effect ninety days from Passage



ENROLLED
Senate Bill No. 475
(By MRS. SPEARS and MR. WISE)

[Passed April 11, 1981; in effect ninety days from passage.]

AN ACT to amend chapter sixteen of the code of West Virginia, one thousand nine hundred thirty-one, as amended, by adding thereto a new article, designated article twenty-four, relating to the establishment and maintenance of a state program for the care, treatment and assistance of all persons in the state suffering from hemophilia; defining hemophilia; stating the purpose and goal of said program; prescribing certain general program requirements and basic principles; relating to program coverage, minimum standards and guidelines; providing for a certain advisory committee on hemophilia, its function and meetings and reimbursement of members; providing for enrollment in said program and requiring a certain consent therefor; providing for when certain payments to hemophiliacs may be made; and giving the state director of health broad general powers, duties and responsibilities with respect to all the foregoing.

Be it enacted by the Legislature of West Virginia:

That chapter sixteen of the code of West Virginia, one thousand nine hundred thirty-one, as amended, be amended by adding thereto a new article, designated article twenty-four, to read as follows:

ARTICLE 24. STATE HEMOPHILIA PROGRAM.

§16-24-1. Definition.

- 1 As used in this article, "hemophilia" means a person's
- 2 bleeding tendency resulting from a genetically determined
- 3 deficiency of a clotting factor in the blood.

§16-24-2. Establishment of state program for care and treatment of hemophilia.

1 The state director of health shall establish and maintain a
2 state hemophilia program for the care, treatment and other
3 assistance of all persons in this state suffering from
4 hemophilia. Such program shall assist such persons who
5 require continuing treatment of blood and blood derivatives
6 to avoid crippling, extensive hospitalization and other effects
7 associated with such condition and shall provide medical
8 care and assistance for hemophiliacs who are unable to pay
9 for their medical expenses despite the existence of various
10 types of private and public insurance programs, government
11 assistance programs or private charitable assistance
12 programs. The director shall establish and maintain
13 standards to determine the eligibility of persons for care,
14 treatment and assistance under the program and for the
15 supervision of all such care, treatment, and assistance
16 provided.

§16-24-3. Purpose of article; goal of program.

1 The purpose of this article and the goal of the program
2 established by this article to increase the availability,
3 accessibility, efficiency and quality of health delivery
4 services for hemophiliacs in West Virginia and to normalize
5 their life-style to the fullest extent possible.

§16-24-4. General program requirements and basic principles.

1 The director shall organize and maintain the program
2 established by this article according to the following
3 requirements:
4 (1) The objectives of the program must be realistic and
5 obtainable and must promote increased quality of life for as
6 many hemophiliacs in this state as funds permit.
7 (2) Priority must be given to activities designed to prevent
8 crippling, reduce the need for hospitalization and normalize
9 to the maximum extent practicable the life-style of as many
10 hemophiliacs as possible.
11 (3) The program must make provision for review by the
12 director of the quality of treatment being given. Review must
13 allow consideration of new medical knowledge, changes in
14 federal and state legislation, rules and regulations and
15 possible alternative sources of funding to insure full
16 representation and protection of the hemophiliacs.

17 (4) Cooperative linkages among providers of services
 18 must be sought and developed. Health care programs must be
 19 publicized and promoted.

20 (5) Patients and their families must have the freedom of
 21 choice in the type of treatment and the place of delivery.

**§16-24-5. General powers, duties and responsibilities of
 director; program coverage.**

1 In carrying out the program established by this article, the
 2 director has the power, duty and responsibility to:

3 (1) Establish and maintain a roster of persons with
 4 hemophilia;

5 (2) Establish and maintain minimum standards for
 6 determining eligibility for care and treatment under the
 7 program, which must require that any resident hemophiliac
 8 may register and participate in the program even if he chooses
 9 to pay the entire cost of blood and blood products himself;

10 (3) Identify hemophilia centers in this state that are
 11 interested in creating or expanding a home care program.
 12 Such centers must provide comprehensive services for
 13 periodic, at least annual, review of registered hemophiliacs;

14 (4) Provide blood products for home care programs,
 15 monitor their usefulness and determine costs of available
 16 blood products and secure such products at the least possible
 17 cost to each patient;

18 (5) Develop a registry of resources for hemophiliacs in
 19 West Virginia and disseminate information thereupon to
 20 patients and the public through educational programs; and

21 (6) Do all other things, not inconsistent with the
 22 provisions of this article, reasonable and necessary or
 23 convenient to carry out the purpose of this article and achieve
 24 the goal of the state hemophilia program.

§16-24-6. Advisory committee on hemophilia.

1 The director shall appoint an advisory committee on
 2 hemophilia composed of knowledgeable physicians,
 3 representatives of the state chapter of the national
 4 hemophilia foundation, if any such chapter is established,
 5 patients, parents of patients and representatives of provider
 6 agencies to advise the director as to the contents and
 7 concerns of the program established by this article and all
 8 other pertinent matters of mutual concern.

9 Such committee shall meet at such times and places as the
 10 director considers necessary or convenient. Each member of

11 the committee shall be reimbursed for all reasonable and
12 necessary expenses actually incurred in carrying out his
13 duties pursuant to this section.

**§16-24-7. Enrollment in program; consent of private physician
required.**

1 Any person meeting the minimum standards for eligibility
2 prescribed by the director may register in the program
3 established by this article. A person may be enrolled in the
4 program only with the consent of his private physician.

**§16-24-8. When payments for care and treatment of
hemophiliacs may be made by director.**

1 All resources reasonably available to the hemophiliac such
2 as private insurance, medicaid payments, aid from other state
3 agency programs and private agency fundings must be used
4 for payment of medical care for the hemophiliac before any
5 funds provided pursuant to the state hemophilia program
6 established by this article are used. Approved participating
7 treatment centers may be reimbursed for services according
8 to rates established by the director for that portion of
9 approved care for the hemophiliac not covered by other
10 insurance or assistance programs. Where such insurance or
11 other assistance funds are available, approved treatment
12 centers shall be required by the director to submit grant
13 requests for such funds. Any center receiving any moneys
14 from the director under the program established by this
15 article must accept and comply with the director's standards
16 hereunder for home care and ongoing patient evaluation.

The Joint Committee on Enrolled Bills hereby certifies that the foregoing bill is correctly enrolled.

R. P. Baylbe
Chairman Senate Committee

Jonny E. Whitlow
Chairman House Committee

Originated in the Senate.

To take effect ninety days from passage.

Todd C. Walls
Clerk of the Senate

C. Blankenship
Clerk of the House of Delegates

Wm. J. St. John
President of the Senate

Thos. M. Bee, Jr.
Speaker House of Delegates

The within *approved* this the *29*
day of *April*, 1981.

John R. Roper
Governor



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