

ASSEMBLY, No. 110

STATE OF NEW JERSEY

PRE-FILED FOR INTRODUCTION IN THE 1996 SESSION

By Assemblyman JONES and Assemblywoman GILL

1 AN ACT concerning the early detection and treatment of sickle cell
2 anemia and other hemoglobinopathies and making an appropriation
3 therefor.

4
5 **BE IT ENACTED** by the Senate and General Assembly of the State
6 of New Jersey:

7
8 1. It is hereby declared to be the public policy of this State that in
9 the interests of public health every effort should be made to detect in
10 newborn infants, sickle cell anemia and other hemoglobinopathies and
11 to treat affected individuals.

12
13 2. All infants born in this State shall be tested for sickle cell anemia
14 and other hemoglobinopathies. The Commissioner of Health and
15 Senior Services shall issue regulations to assure that newborns are so
16 tested in a manner approved by the commissioner. The commissioner
17 shall ensure that treatment services are available to all identified
18 individuals. The Department of Health and Senior Services may
19 charge a reasonable fee for the tests performed pursuant to this act.
20 The amount of the fee and the procedures for collecting the fee shall
21 be determined by the commissioner. The commissioner shall apply all
22 revenues collected from the fees to the testing and treatment
23 procedures performed pursuant to this act.

24 The commissioner may also require testing of newborn infants for
25 other genetic disorders if reliable and efficient testing techniques are
26 available. If the commissioner determines that an additional test shall
27 be required, 90 days prior to requiring the test he shall advise the
28 President of the Senate, Speaker of the General Assembly and
29 chairmen of the standing reference committees on appropriations and
30 health of his determination.

31 The commissioner shall provide a program of reviewing and
32 following up on positive cases in order that measures may be taken to
33 treat these disorders.

34 Information on newborn infants and their families compiled
35 pursuant to this section may be used by the department and agencies
36 designated by the commissioner for the purposes of carrying out this

1 act, but otherwise the information shall be confidential and not
2 divulged or made public so as to disclose the identity of any person to
3 which it relates, except as provided by law. The department shall
4 conduct an intensive educational and training program among
5 physicians, hospitals, public health nurses and the public concerning
6 sickle cell anemia and other hemoglobinopathies. This program shall
7 include information concerning the nature of the disorders, testing for
8 the detection of these disorders and treatment modalities for these
9 disorders.

10 The provisions of this section shall not apply if the parents of a
11 newborn infant object to the testing on the grounds that it would
12 conflict with their religious tenets or practices.

13

14 3. There is appropriated \$375,000 from the General Fund to the
15 Department of Health and Senior Services to effectuate the purposes
16 of this act.

17

18 4. This act shall take effect immediately.

19

20

21

22

23 Provides for the detection and treatment of sickle cell anemia in
24 newborn children, appropriates \$375,000.