ASSEMBLY, No. 2512

STATE OF NEW JERSEY

219th LEGISLATURE

INTRODUCED FEBRUARY 3, 2020

Sponsored by:
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District 21 (Morris, Somerset and Union)
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SYNOPSIS

Provides for screening newborn infants for genetic mutations associated with hereditary hemochromatosis.

CURRENT VERSION OF TEXT

As introduced.

(Sponsorship Updated As Of: 2/24/2020)

AN ACT concerning genetic screening of newborn infants and supplementing Title 26 of the Revised Statutes.

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

1. a. All infants born in this State shall be tested for the genetic mutations associated with the development of hereditary hemochromatosis.

b. If an infant tests positive for one or more of the genetic mutations associated with the development of hereditary hemochromatosis the medical care provider overseeing care of the infant shall provide the parents of the infant with:

(1) Genetic counseling by a genetic counselor licensed pursuant to P.L.2009, c.41 (C.45:9-37.111 et seq.); and

(2) Information concerning:

(a) the potential that they, their children, and their parents may carry one or more of the genetic mutations associated with the development of hereditary hemochromatosis;

(b) the risk that they, their parents, and their children may develop hereditary hemochromatosis;

(c) the procedures for and benefits of undergoing genetic screening for the genetic mutations associated with the development of hereditary hemochromatosis;

(d) the procedures for and benefits of periodic screening for the development of hereditary hemochromatosis;

(e) the symptoms of hereditary hemochromatosis; and

(f) the treatments available for hereditary hemochromatosis.

c. Notwithstanding the provisions of section 7 of P.L.1996, c.126 (C.10:5-46), the results of a test performed pursuant to subsection a. of this section for an infant found to carry two genetic mutations associated with the development of hereditary hemochromatosis may be retained by the provider until that infant has reached the age of 18 years, at which time the hospital, birthing facility, or medical facility in charge of the record shall provide the subject of the record with information concerning:

(a) the risk that the person may develop hereditary hemochromatosis;

(b) the symptoms of hereditary hemochromatosis;

(c) the procedures for and benefits of periodic screening for the development of hereditary hemochromatosis; and

(d) the treatments available for hereditary hemochromatosis.

2. This act shall take effect on the 180th day after enactment, except that the Commissioner of Health shall take such anticipatory administrative action in advance thereof as shall be necessary for its implementation.

STATEMENT

This bill would require that all infants born in this State be tested for the genetic mutations associated with the development of hereditary hemochromatosis, which is a disease that causes the body to absorb excessive amounts of iron. The excess iron is stored in the body's organs and tissues and may, if left untreated, result in organ damage.

According to the federal Centers for Disease Control and Prevention (CDC), the greatest risk factor for developing hereditary hemochromatosis is inheriting two copies, one from each parent, of a mutated HFE gene. Not every person who inherits two copies of the mutated HFE gene will develop hereditary hemochromatosis; however, a person with two copies of the mutated gene has a much greater risk of developing the disease and should undergo periodic blood screening to detect signs of excess iron buildup. Similarly, a person who inherits one copy of the mutated gene will usually not develop hereditary hemochromatosis; however, the person is said to be a "carrier" and may pass the gene on to their children. If both parents are carriers, there is a risk their children will inherit two copies of the mutated gene and potentially develop hereditary hemochromatosis. Additionally, when a person is found to carry one or more of the mutated genes, that person's parents and siblings may carry one or two copies of the mutated gene and may be at risk for developing hereditary hemochromatosis.

According to the CDC, the symptoms of hereditary hemochromatosis rarely appear before adulthood. Symptoms may vary depending on which organs are affected by the excess iron buildup, and early symptoms often resemble those of other common diseases, which may make the condition difficult to detect before irreversible organ damage has occurred.

Once detected, hereditary hemochromatosis is highly treatable by periodically drawing blood from the arm, a process known as phlebotomy, until the person's iron levels return to normal. Once iron levels return to normal, periodic phlebotomy sessions may be necessary to maintain proper iron levels. The CDC suggests that, if treatment begins before organ damage occurs, the person can expect to live a normal lifespan.

Under the bill, if an infant is found to have one or more of the genetic mutations associated with hereditary hemochromatosis, the medical care provider overseeing care of the infant would provide the parents with genetic counseling and information concerning the risk factors, symptoms, screening procedures, and the treatments available for hereditary hemochromatosis. The parents would also be provided with information concerning the risk that they, their parents, and their children may carry one or more of the genetic mutations and information about genetic testing. If an infant is found to carry two mutated genes associated with the development

of hereditary hemochromatosis, the bill would permit the medical care provider to retain the genetic test results until such time as the tested infant turns age 18. At that time, the hospital, birthing facility, or medical facility would provide that person with information concerning the risk that the person may develop hereditary hemochromatosis, the symptoms of hereditary hemochromatosis, the procedures for, and benefits of, periodic screening for the development of hereditary hemochromatosis, and the available treatments for hereditary hemochromatosis.