

116TH CONGRESS
2D SESSION

S. 4249

To ensure the protection of human genetic information collected as a result of diagnostic testing for COVID–19.

IN THE SENATE OF THE UNITED STATES

JULY 21, 2020

Mr. TILLIS introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To ensure the protection of human genetic information collected as a result of diagnostic testing for COVID–19.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. PROTECTION OF HUMAN GENETIC INFORMA-**
4 **TION.**

5 (a) IN GENERAL.—Notwithstanding any other provi-
6 sion of law, the Secretary of Health and Human Services
7 shall ensure that no person may collect, store, analyze, dis-
8 seminate, or otherwise make use of, or benefit from, any
9 human genetic information collected as a result of diag-
10 nostic testing for COVID–19, for any incidental use, or

1 any reason other than such diagnostic or serologic testing,
2 except with the express, written, informed consent of the
3 individual being tested.

4 (b) ENFORCEMENT.—Any person who violates sub-
5 section (a) shall be subject to a civil monetary penalty of
6 not more than \$100 for each such violation.

7 (c) DEFINITIONS.—In this section—

8 (1) the term “genetic information” has the
9 meaning given such term in section 160.103 of title
10 45, Code of Federal Regulations (or any successor
11 regulations); and

12 (2) the term “incidental” means any action
13 taken by any person, directly or indirectly, to obtain
14 genetic information from an individual, for any pur-
15 pose, other than the purpose specifically authorized
16 by the living individual from whom the specimen has
17 its biological origin or another designated individual
18 if the individual is a minor or is incapacitated, or if
19 the individual is deceased, the individual’s next of
20 kin.

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