

118TH CONGRESS
1ST SESSION

H. R. 6412

To amend title XXVII of the Public Health Service Act to provide certain informational resources related to Down syndrome.

IN THE HOUSE OF REPRESENTATIVES

NOVEMBER 14, 2023

Mr. MOLINARO (for himself, Ms. BUDZINSKI, and Mr. LAWLER) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend title XXVII of the Public Health Service Act to provide certain informational resources related to Down syndrome.

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. SHORT TITLE.**

4 This Act may be cited as the “Down Syndrome Diag-
5 nosis Act”.

6 **SEC. 2. PROVIDING INFORMATIONAL RESOURCES RELATED**
7 **TO DOWN SYNDROME.**

8 (a) IN GENERAL.—Subpart II of part A of title
9 XXVII of the Public Health Service Act (42 U.S.C.

1 300gg–11 et seq.) is amended by adding at the end the
2 following new section:

3 **“SEC. 2730. INFORMATIONAL RESOURCES RELATED TO**
4 **DOWN SYNDROME.**

5 “(a) IN GENERAL.—In the case of an individual en-
6 rolled under a group health plan or group or individual
7 health insurance coverage who is diagnosed with Down
8 syndrome while so enrolled (or who is pregnant and is
9 given a diagnosis of Down syndrome with respect to the
10 fetus while so enrolled), not later than 60 days after such
11 plan or coverage is made aware (through claims data or
12 otherwise) of the relevant diagnosis, such plan or coverage
13 shall provide the informational resources described in sub-
14 section (b) to—

15 “(1) the individual; or

16 “(2) if the individual is under the age of 18, a
17 parent or legal guardian of the individual.

18 “(b) INFORMATIONAL RESOURCES DESCRIBED.—For
19 purposes of subsection (a), the informational resources de-
20 scribed in this subsection are the following:

21 “(1) Written information about Down syn-
22 drome, including information on the range of phys-
23 ical, developmental, educational, and psychosocial
24 outcomes for individuals living with Down syndrome,
25 that—

1 “(A) is up-to-date, evidence-based, and cul-
2 turally and linguistically appropriate for the in-
3 dividual; and

4 “(B) was developed by—

5 “(i) medical experts or representatives
6 of national medical or genetics organiza-
7 tions; and

8 “(ii) disability experts or representa-
9 tives of patient advocacy groups.

10 “(2) Contact information for 1 or more organi-
11 zations that specialize in Down syndrome support,
12 such as the National Down Syndrome Congress, the
13 National Down Syndrome Society, or the Global
14 Down Syndrome Foundation.”.

15 (b) EFFECTIVE DATE.—The amendment made by
16 subsection (a) shall apply with respect to plan years begin-
17 ning on or after January 1, 2024.

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