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(Original Signature of Member)

119TH CONGRESS
2D SESSION

H. R. _____

To amend title XIX of the Social Security Act to clarify that whole genome and whole exome sequencing for children with certain medical needs is covered under the Medicaid program.

IN THE HOUSE OF REPRESENTATIVES

Mr. PETERS introduced the following bill; which was referred to the Committee on _____

A BILL

To amend title XIX of the Social Security Act to clarify that whole genome and whole exome sequencing for children with certain medical needs is covered under the Medicaid program.

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 “Genomic Answers for
5 Children’s Health Act of 2026”.

1 **SEC. 2. CLARIFYING THAT WHOLE GENOME AND WHOLE**
2 **EXOME SEQUENCING FOR CHILDREN WITH**
3 **CERTAIN MEDICAL NEEDS IS COVERED**
4 **UNDER THE MEDICAID PROGRAM.**

5 (a) IN GENERAL.—Section 1905 of the Social Secu-
6 rity Act (42 U.S.C. 1396d) is amended—

7 (1) in subsection (r)—

8 (A) by redesignating paragraph (5) as
9 paragraph (6); and

10 (B) by inserting after paragraph (4) the
11 following new paragraph:

12 “(5) Whole genome sequencing and whole
13 exome sequencing (as defined in subsection (kk)),
14 whether furnished in the inpatient or outpatient set-
15 ting, if ordered by a physician or other provider act-
16 ing within the provider’s scope of practice under
17 State law as a first-tier test for an individual sus-
18 pected to have a genetic disorder, rare disease, or a
19 health condition of unknown origin, including 1 or
20 more congenital anomalies, a global developmental
21 delay, or an intellectual disability.”; and

22 (2) by adding at the end the following new sub-
23 section:

24 “(kk) WHOLE GENOME SEQUENCING AND WHOLE
25 EXOME SEQUENCING.—For purposes of subsection (r)(5),

1 the term ‘whole genome sequencing and whole exome se-
2 quencing’—

3 “(1) means the determination of a sequence of
4 deoxyribonucleic acid bases in the genome taken or
5 derived from an individual, and, if for the primary
6 benefit of the individual’s diagnosis or treatment, a
7 first degree biological relative or relatives of such in-
8 dividual for the purpose of determining whether 1 or
9 more potentially disease-causing genetic variants are
10 present in the genome of such individual or such bio-
11 logical first-degree relative; and

12 “(2) includes—

13 “(A) the sequencing of the whole genome
14 or the whole exome; and

15 “(B) any analysis, interpretation, and data
16 report derived from such sequencing.”.

17 (b) ADDITIONAL UPDATES.—Section 1902(a) of the
18 Social Security Act (42 U.S.C. 1396a(a)) is amended—

19 (1) in paragraph (88), by striking “and” at the
20 end;

21 (2) in paragraph (89), by striking the period
22 and inserting “; and”; and

23 (3) by inserting after paragraph (89) the fol-
24 lowing new paragraph:

1 “(90) provide that payment for whole genome
2 sequencing and whole exome sequencing (as defined
3 in section 1905(kk)) is made separately and is not
4 bundled as part of payment for any other medical
5 assistance.”.

6 (c) OUTREACH AND EDUCATION.—For purposes of
7 promoting awareness of and access to whole genome and
8 exome sequencing under section 1905(r) of the Social Se-
9 curity Act (42 U.S.C. 1396d(r)), the Secretary of Health
10 and Human Services shall—

11 (1) convene national organizations (including at
12 least those organizations representing pediatricians,
13 specialists in pediatric rare diseases, children’s hos-
14 pitals, geneticists, genetic counselors, laboratory test
15 developers), States, hospitals and health systems, in-
16 dividuals with rare diseases, and those national or-
17 ganizations representing Medicaid managed care or-
18 ganizations to identify challenges and opportunities
19 in implementation of the amendments made by this
20 section, including potential best practices that mini-
21 mize denials of claims for medical assistance under
22 the State plan under title XIX of such Act resulting
23 from use of prior authorization or administrative re-
24 quirements.

1 (2) conduct outreach to national organizations
2 (including at least those organizations representing
3 hospitals, health systems, children’s hospitals, pedia-
4 tricians, and geneticists), States, national organiza-
5 tions representing Medicaid managed care
6 organizations, national organizations representing
7 rare disease patients and families, and national or-
8 ganizations representing Medicaid-eligible children
9 and their families to ensure they are aware of the
10 early and periodic screening, diagnostic, and treat-
11 ment services benefit under title XIX of such Act
12 and can benefit from access to required screenings
13 and necessary treatment services; and

14 (3) not later than 2 years after the date of the
15 enactment of this Act, publish on the public website
16 of the Department of Health and Human Services a
17 report that includes—

18 (A) payment amounts for whole genome
19 sequencing and whole exome sequencing under
20 each State plan under title XIX of such Act;
21 and

22 (B) information relating to the number of
23 children receiving such sequencing under such
24 State plans, health outcomes, types of services

1 provided as a result of such sequencing, and
2 other such relevant information.

3 (d) REPORT.—Not later than 2 years after the date
4 of the enactment of this Act, the Comptroller General of
5 the United States shall do the following:

6 (1) Collect and analyze feedback regarding im-
7 plementation of the amendments made by this Act
8 from the organizations and entities described in
9 paragraph (1) or (2) of subsection (b), including—

10 (A) experiences in accessing whole genome
11 sequencing and whole exome sequencing and re-
12 sults pursuant to such amendments, including
13 any barriers to such access;

14 (B) changes to care or services furnished
15 after such sequencing;

16 (C) identification of remaining challenges,
17 if any, related to access to such sequencing for
18 individuals eligible for early and periodic
19 screening, diagnostic, and treatment services
20 under the Medicaid program; and

21 (D) health professional awareness of such
22 amendments.

23 (2) Assess the following for impacts on access
24 to such sequencing under such program for such in-
25 dividuals:

1 (A) Prior authorization, which may include
2 assessment of impacts related to delay of care
3 and uncertainty or surprise of payment.

4 (B) Workforce and reimbursement chal-
5 lenges for genetic counselors.

6 (C) The extent to which market cost is
7 aligned with the Medicare clinical laboratory fee
8 schedule and the degree to which the Secretary
9 of Health and Human Services' adjustment of
10 the fee schedule might more accurately reflect
11 market realities and support affordability.

12 (3) Make recommendations to the Secretary of
13 Health and Human Services relating to additional
14 guidance or improvements that may be made based
15 on the feedback collected under paragraph (1) and
16 the assessment described in paragraph (2).

17 (e) EFFECTIVE DATE.—The amendments made by
18 this section shall apply beginning January 1, 2027.