

**[DISCUSSION DRAFT]**

111<sup>TH</sup> CONGRESS  
1<sup>ST</sup> SESSION

**H. R.** \_\_\_\_\_

To provide for a disregard under the Supplemental Security Income program of compensation for participation in clinical trials for rare diseases or conditions.

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IN THE HOUSE OF REPRESENTATIVES

Mr. MARKEY of Massachusetts (for himself and Mr. STEARNS) introduced the following bill; which was referred to the Committee on

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**A BILL**

To provide for a disregard under the Supplemental Security Income program of compensation for participation in clinical trials for rare diseases or conditions.

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

1 **SECTION 1. DISREGARD UNDER THE SUPPLEMENTAL SE-**  
2 **CURITY INCOME PROGRAM OF COMPENSA-**  
3 **TION FOR PARTICIPATION IN CLINICAL**  
4 **TRIALS FOR RARE DISEASES OR CONDITIONS.**

5 (a) INCOME DISREGARD.—Section 1612(b) of the So-  
6 cial Security Act (42 U.S.C. 1382a(b)) is amended—

7 (1) by striking “and” at the end of paragraph  
8 (24);

9 (2) by striking the period at the end of para-  
10 graph (25) and inserting “; and”; and

11 (3) by adding at the end the following:

12 “(26) the first \$2,000 per year received by such  
13 individual (or such spouse) for participation in a  
14 clinical trial to test a treatment for a rare disease  
15 or condition (within the meaning of section 5(b)(2)  
16 of the Orphan Drug Act), that—

17 “(A) has been reviewed and approved by  
18 an institutional review board that—

19 “(i) is established to protect the rights  
20 and welfare of human subjects partici-  
21 pating in research; and

22 “(ii) meet the standards for such bod-  
23 ies set forth in part 46 of title 45, Code of  
24 Federal Regulations, and

1           “(B) meets the standards for protection of  
2           human subjects for clinical research (as set  
3           forth in such part).”.

4           (b) RESOURCE DISREGARD.—Section 1613(a) of  
5 such Act (42 U.S.C. 1382b(a)) is amended—

6           (1) by striking “and” at the end of paragraph  
7           (15);

8           (2) by striking the period at the end of para-  
9           graph (16) and inserting “; and”; and

10           (3) by inserting after paragraph (16) the fol-  
11           lowing:

12           “(17) the first \$2,000 per year received by such  
13           individual (or such spouse), as described in section  
14           1612(b)(26).”.

15           (c) EFFECTIVE DATE.—The amendments made by  
16 this section shall apply to benefits for calendar months  
17 beginning after the 30-day period that begins with the  
18 date of the enactment of this Act.