

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

# H. R. 1441

To amend title XIX of the Social Security Act to allow States to permit certain Medicaid eligible individuals who have extremely high annual lifelong orphan drug costs to continue on Medicaid notwithstanding increased income.

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## IN THE HOUSE OF REPRESENTATIVES

MARCH 11, 2009

Mr. MARCHANT (for himself, Mrs. EMERSON, Mr. SESSIONS, Ms. GRANGER, Mr. BRALEY of Iowa, and Mr. ORTIZ) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To amend title XIX of the Social Security Act to allow States to permit certain Medicaid eligible individuals who have extremely high annual lifelong orphan drug costs to continue on Medicaid notwithstanding increased income.

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 “Ryan Dant Health  
5 Care Opportunity Act of 2009”.

1 **SEC. 2. STATE OPTION TO DISREGARD CERTAIN INCOME IN**  
2 **PROVIDING CONTINUED MEDICAID COV-**  
3 **ERAGE FOR CERTAIN INDIVIDUALS WITH EX-**  
4 **TREMELY HIGH PRESCRIPTION COSTS.**

5 Section 1902(e) of the Social Security Act (42 U.S.C.  
6 1396b(e)), as amended by section 203(a) of the Children’s  
7 Health Insurance Program Reauthorization Act of 2009  
8 (Public Law 111–3), is amended by adding at the end the  
9 following new paragraph:

10 “(14)(A) At the option of the State, in the case  
11 of an individual with extremely high prescription  
12 drug costs described in subparagraph (B) who has  
13 been determined (without the application of this  
14 paragraph) to be eligible for medical assistance  
15 under this title, the State may, in redetermining the  
16 individual’s eligibility for medical assistance under  
17 this title, disregard any family income of the indi-  
18 vidual to the extent such income is less than an  
19 amount that is specified by the State and does not  
20 exceed the amount specified in subparagraph (C), or,  
21 if greater, income equal to the cost of the orphan  
22 drugs described in subparagraph (B)(iii).

23 “(B) An individual with extremely high pre-  
24 scription drug costs described in this subparagraph  
25 for a 12-month period is an individual—

1           “(i) who is covered under health insurance  
2           or a health benefits plan that has a maximum  
3           lifetime limit of not less than \$1,000,000 which  
4           includes all prescription drug coverage;

5           “(ii) who has exhausted all available pre-  
6           scription drug coverage under the plan as of the  
7           beginning of such period;

8           “(iii) who incurs (or is reasonably expected  
9           to incur) on an annual basis during the period  
10          costs for orphan drugs in excess of the amount  
11          specified in subparagraph (C) for the period;  
12          and

13          “(iv) whose annual family income (deter-  
14          mined without regard to this paragraph) as of  
15          the beginning of the period does not exceed 75  
16          percent of the amount incurred for such drugs  
17          (as described in clause (iii)).

18          “(C) The amount specified in this subpara-  
19          graph for a 12-month period beginning in—

20                  “(i) 2009 or 2010, is \$200,000; or

21                  “(ii) a subsequent year, is the amount  
22                  specified in clause (i) (or this subparagraph) for  
23                  the previous year increased by the annual rate  
24                  of increase in the medical care component of  
25                  the consumer price index (U.S. city average) for

1 the 12-month period ending in August of the  
2 previous year.

3 Any amount computed under clause (ii) that is not  
4 a multiple of \$1,000 shall be rounded to the nearest  
5 multiple of \$1,000.

6 “(D) In applying this paragraph, amounts in-  
7 curred for prescription drugs for cosmetic purposes  
8 shall not be taken into account.

9 “(E) With respect to an individual described in  
10 subparagraph (A), notwithstanding section 1916, the  
11 State plan—

12 “(i) shall provide for the application of  
13 cost-sharing that is at least nominal as deter-  
14 mined under section 1916; and

15 “(ii) may provide, consistent with section  
16 1916A, for such additional cost-sharing as does  
17 not exceed a maximum level of cost-sharing  
18 that is specified by the Secretary and is ad-  
19 justed by the Secretary on an annual basis.

20 “(F) A State electing the option under this  
21 paragraph shall provide for a determination on an  
22 individual’s application for continued medical assist-  
23 ance under this title within 30 days of the date the  
24 application is filed with the State.

25 “(G) In this paragraph:

1           “(i) The term ‘orphan drugs’ means pre-  
2           scription drugs designated under section 526 of  
3           the Federal Food, Drug, and Cosmetic Act (21  
4           U.S.C. 360bb) as a drug for a rare disease or  
5           condition.

6           “(ii) The term ‘health benefits plan’ in-  
7           cludes coverage under a plan offered under a  
8           State high risk pool.”.

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