

111TH CONGRESS  
1ST SESSION

# H. R. 2538

To amend the Public Health Service Act to provide for the establishment and maintenance of an undiagnosed diseases registry.

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## IN THE HOUSE OF REPRESENTATIVES

MAY 21, 2009

Mr. CARTER (for himself and Mr. BURGESS) introduced the following bill;  
which was referred to the Committee on Energy and Commerce

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## A BILL

To amend the Public Health Service Act to provide for the establishment and maintenance of an undiagnosed diseases registry.

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 “Charles August ‘CAL’  
5       Long Undiagnosed Diseases Registry Act of 2009”.

6       **SEC. 2. REGISTRY OF UNDIAGNOSED DISEASES.**

7       (a) IN GENERAL.—Title III of the Public Health  
8       Service Act (42 U.S.C. 241 et seq.) is amended by insert-  
9       ing after section 317T the following:

1 **“SEC. 317U. UNDIAGNOSED DISEASES REGISTRY.**

2       “(a) ESTABLISHMENT.—The Secretary, acting  
3 through the Director of the Centers for Disease Control  
4 and Prevention, shall establish and maintain an  
5 undiagnosed diseases registry (in this section referred to  
6 as the ‘registry’).

7       “(b) CONTENT OF REGISTRY.—The Secretary shall  
8 include in the registry such information respecting  
9 undiagnosed diseases as the Secretary deems appropriate  
10 for the purpose of facilitating the early recognition, pre-  
11 vention, treatment, cure, and control of such diseases.

12       “(c) AVAILABILITY.—For the purpose described in  
13 subsection (b), the Secretary may make the information  
14 in the registry publicly available, except the Secretary  
15 shall not publicly disclose—

16               “(1) individually identifiable information; or

17               “(2) trade secrets or commercial or financial in-  
18 formation obtained from a person and privileged or  
19 confidential, as provided in section 552(b)(4) of title  
20 5, United States Code.

21       “(d) AUTHORIZATION OF APPROPRIATIONS.—To  
22 carry out this section, there are authorized to be appro-  
23 priated \$5,000,000 for fiscal year 2010 and such sums  
24 as may be necessary for each of fiscal years 2011 through  
25 2015.”.

1       (b) FIRST OPERATION OF REGISTRY.—The Secretary  
2 of Health and Human Services, acting through the Direc-  
3 tor of the Centers for Disease Control and Prevention,  
4 shall ensure that the undiagnosed diseases registry estab-  
5 lished pursuant to section 317U of the Public Health  
6 Service Act, as added by subsection (a), becomes oper-  
7 ational not later than one year after the date of the enact-  
8 ment of this Act.

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