

116TH CONGRESS
2D SESSION

H. R. 6238

To amend the Internal Revenue Code of 1986 to restore the amount of
the orphan drug tax credit, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MARCH 12, 2020

Mr. GOTTHEIMER (for himself and Mr. UPTON) introduced the following bill;
which was referred to the Committee on Ways and Means, and in addition
to the Committee on Energy and Commerce, for a period to be subsequently
determined by the Speaker, in each case for consideration of
such provisions as fall within the jurisdiction of the committee concerned

A BILL

To amend the Internal Revenue Code of 1986 to restore
the amount of the orphan drug tax credit, and for other
purposes.

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 “Cameron’s Law”.

1 **SEC. 2. RESTORATION OF AMOUNT OF ORPHAN DRUG TAX**

2 **CREDIT.**

3 (a) IN GENERAL.—Section 45C(a) of the Internal
4 Revenue Code of 1986 is amended by striking “25 per-
5 cent” and inserting “50 percent”.

6 (b) EFFECTIVE DATE.—The amendment made by
7 this section shall apply to taxable years beginning after
8 the date of the enactment of this Act.

9 **SEC. 3. CDC STUDY ON SURVEILLANCE INFRASTRUCTURE**
10 **FOR RARE DISEASES AND CONDITIONS.**

11 (a) STUDY.—Not later than 1 year after the date of
12 enactment of this Act, the Director of the Centers for Dis-
13 ease Control and Prevention (in this section referred to
14 as the “Director”) shall complete a study on enhancing
15 and expanding the infrastructure to track the epidemi-
16 ology of rare diseases and conditions, including with re-
17 spect to the following:

- 18 (1) Rates of mortality.
- 19 (2) Potential for research and treatment.
- 20 (3) Demographics.
- 21 (4) Diagnosis and progression markers.
- 22 (5) The history of the disease or condition.
- 23 (6) Detection management.

24 (b) CONSULTATION.—In conducting the study re-
25 quired by subsection (a), the Director shall consult with
26 relevant experts, including—

1 (1) epidemiologists with experience in disease
2 surveillance;

3 (2) representatives of national voluntary health
4 associations;

5 (3) health information technology experts or
6 other information management specialists;

7 (4) clinicians with expertise in rare diseases or
8 conditions;

9 (5) research scientists with expertise in rare
10 diseases or conditions, or experience conducting
11 translational research or utilizing surveillance sys-
12 tems for scientific research purposes; and

13 (6) patients, and caregivers of patients, with
14 rare diseases or conditions.

15 (c) REPORT.—Not later than 3 months after com-
16 pleting the study required by subsection (a), the Director
17 shall submit a report to the Congress on the results of
18 the study.

19 (d) DEFINITION.—In this section, the terms “rare
20 diseases and conditions” and “rare diseases or conditions”
21 refer to human diseases and conditions that are—

22 (1) a rare disease or condition, as defined in
23 section 526 of the Federal Food, Drug, and Cos-
24 metic Act (21 U.S.C. 360bb); or

1 (2) determined by the Director to be rare and
2 lacking in treatment options, so as to warrant con-
3 sideration in the study required by subsection (a).

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