

117TH CONGRESS
1ST SESSION

H. R. 2623

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

APRIL 16, 2021

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 FEASIBILITY STUDY ON SURVEILLANCE INFRA-**
10 **STRUCTURE FOR RARE DISEASES AND CON-**
11 **DITIONS.**

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

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

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

4 (1) epidemiologists with experience in disease
5 surveillance;

6 (2) representatives of national voluntary health
7 associations;

8 (3) health information technology experts or
9 other information management specialists;

10 (4) clinicians with expertise in rare diseases or
11 conditions;

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

16 (6) patients, and caregivers of patients, with
17 rare diseases or conditions.

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

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

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

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

○