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(Original Signature of Member)

116TH CONGRESS
1ST SESSION

H. R. _____

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

Mr. GOTTHEIMER introduced the following bill; which was referred to the Committee on _____

A BILL

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

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as ''Cameron's Law''.

SEC. 2. RESTORATION OF AMOUNT OF ORPHAN DRUG TAX CREDIT.

(a) IN GENERAL.—Section 45C(a) of the Internal Revenue Code of 1986 is amended by striking ''25 percent'' and inserting ''50 percent''.

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

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

(a) STUDY.—Not later than 1 year after the date of enactment of this Act, the Director of the Centers for Disease Control and Prevention (in this section referred to as the ''Director'') shall complete a study on enhancing and expanding the infrastructure to track the epidemiology of rare diseases and conditions, including with respect to the following:

(1) Rates of mortality.

(2) Potential for research and treatment.

(3) Demographics.

(4) Diagnosis and progression markers.

(5) The history of the disease or condition.

(6) Detection management.

(b) CONSULTATION.—In conducting the study required by subsection (a), the Director shall consult with relevant experts, including—

(1) epidemiologists with experience in disease surveillance;

(2) representatives of national voluntary health associations;

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

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

(5) research scientists with expertise in rare diseases or conditions, or experience conducting translational research or utilizing surveillance systems for scientific research purposes; and

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

(c) REPORT.—Not later than 3 months after completing the study required by subsection (a), the Director shall submit a report to the Congress on the results of the study.

(d) DEFINITION.—In this section, the terms ''rare diseases and conditions'' and ''rare diseases or conditions'' refer to human diseases and conditions that are—

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

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