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(Original Signature of Member)

117TH CONGRESS
2D SESSION

H. R. _____

To amend the Public Health Service Act to authorize the Secretary of Health and Human Services to carry out a program of research related to cerebral palsy, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

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

A BILL

To amend the Public Health Service Act to authorize the Secretary of Health and Human Services to carry out a program of research related to cerebral palsy, 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 the “Cerebral Palsy Re-
5 search Program Authorization Act of 2022”.

6 **SEC. 2. FINDINGS.**

7 Congress finds the following:

1 (1) Cerebral palsy is the most common motor
2 disability in children, affecting more than 1,000,000
3 Americans, 1 in 345 children, and over 17,000,000
4 people worldwide.

5 (2) In the United States, more than 10,000 ba-
6 bies are diagnosed with cerebral palsy each year.

7 (3) Cerebral palsy is a broad group of disorders
8 disrupting a person's ability to move, sit, stand,
9 walk, talk, and use their hands.

10 (4) In more than 80 percent of cases, the cause
11 of cerebral palsy is unknown.

12 (5) Seventy-five percent of individuals with cer-
13 ebral palsy also have 1 or more additional develop-
14 mental disabilities including epilepsy, intellectual dis-
15 abilities, communication problems, learning and at-
16 tention disorders, chronic pain, autism, hearing dis-
17 orders, and visual impairments or blindness.

18 (6) Children with cerebral palsy are more likely
19 to die from the flu and related viruses, including
20 COVID-19, than children without neurologic dis-
21 orders.

22 (7) There is no consensus of best practices for
23 a person with cerebral palsy at the time of diagnosis
24 or through the life span.

1 (8) It is estimated that the lifetime care and
2 medical costs for all people with cerebral palsy who
3 were born in 2000 alone will total more than
4 \$13,500,000,000. The loss of productivity and lost
5 wages of the individual with cerebral palsy and their
6 family members is more than \$35,000,000,000.

7 (9) There is no known cure for cerebral palsy,
8 and in most cases, it is not preventable.

9 **SEC. 3. CEREBRAL PALSY RESEARCH.**

10 Title III of the Public Health Service Act is amended
11 by inserting after section 317C of such Act (42 U.S.C.
12 247b–4) the following new section:

13 **“SEC. 317C–1. CEREBRAL PALSY RESEARCH.**

14 “(a) IN GENERAL.—The Secretary, acting through
15 the Director of the Centers for Disease Control and Pre-
16 vention, and in consultation with other Federal agencies
17 and partners, shall carry out (directly or through grants
18 or contracts) a program of research related to cerebral
19 palsy, including—

20 “(1) research on—

21 “(A) the most promising avenues of cere-
22 bral palsy diagnosis and treatment;

23 “(B) factors that may mitigate the preva-
24 lence of cerebral palsy; and

1 “(C) the health care and societal costs of
2 cerebral palsy;

3 “(2) public health surveillance; and

4 “(3) other research that the Director of the
5 Centers for Disease Control and Prevention deter-
6 mines to be appropriate to provide education and
7 training for health professionals and the general
8 public for purposes of diagnosing, treating, and ex-
9 plaining the causes, prevalence, and life-long effects
10 of cerebral palsy.

11 “(b) TECHNICAL ASSISTANCE.—The Secretary may
12 (directly or through grants or contracts) provide technical
13 assistance to public and nonprofit private entities in fur-
14 therance of research under this section.

15 “(c) EVALUATIONS.—The Secretary shall (directly or
16 through grants or contracts) provide for the evaluation of
17 activities under subsection (a) in order to determine the
18 extent to which such activities have been effective, includ-
19 ing evaluation of the effects of such activities on various
20 demographic populations.

21 “(d) AUTHORIZATION OF APPROPRIATIONS.—To
22 carry out this section, there is authorized to be appro-
23 priated \$5,000,000 for each of fiscal years 2023 through
24 2028.”.

1 **SEC. 4. UPDATING STRATEGIC PLAN FOR CEREBRAL PALSY**
2 **RESEARCH.**

3 (a) IN GENERAL.—Not later than 1 year after the
4 date of enactment of this Act, the Director of the National
5 Institutes of Health, acting through the Director of the
6 National Institute of Neurological Disorders and Stroke
7 and the Director Eunice Kennedy Shriver National Insti-
8 tute of Child Health and Human Development—

9 (1) shall conduct a strategic workshop with key
10 stakeholders to provide updates on promising re-
11 search performed to date with the goal of further re-
12 fining the specific opportunities that were identified
13 in the “NINDS/NICHHD Strategic Plan for Cerebral
14 Palsy Research” dated September 30, 2017 (or any
15 successor strategic plan);

16 (2) shall update such strategic plan (or any
17 successor strategic plan) to include—

18 (A) new research opportunities that are
19 identified in the workshop under paragraph (1);

20 (B) a process and timeline for soliciting
21 proposals for research on cerebral palsy;

22 (C) implementation and clinical studies
23 aimed at early detection and intervention, com-
24 parative effectiveness, and functional outcomes;
25 and

26 (D) surveillance;

1 (3) may include in such updated strategic plan
2 a focus on basic and translational discoveries, in-
3 cluding with respect to—

4 (A) neuroprotective medicine;

5 (B) regenerative medicine and mechanisms
6 of neuroplasticity; and

7 (C) genomics; and

8 (4) shall publish the updated strategic plan.

9 (b) AUTHORIZATION OF APPROPRIATIONS.—To carry
10 out this section, there is authorized to be appropriated
11 \$500,000 for each of fiscal years 2023 and 2024.