

## 117TH CONGRESS H.R. 7265

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

March 29, 2022

Mr. COHEN (for himself, Mr. FITZPATRICK, and Mr. CLEAVER) introduced the following bill; which was referred to the Committee on Energy and Commerce

## 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.
  - (2) In the United States, more than 10,000 babies are diagnosed with cerebral palsy each year.
    - (3) Cerebral palsy is a broad group of disorders disrupting a person's ability to move, sit, stand, walk, talk, and use their hands.
  - (4) In more than 80 percent of cases, the cause of cerebral palsy is unknown.
  - (5) Seventy-five percent of individuals with cerebral palsy also have 1 or more additional developmental disabilities including epilepsy, intellectual disabilities, communication problems, learning and attention disorders, chronic pain, autism, hearing disorders, and visual impairments or blindness.
  - (6) Children with cerebral palsy are more likely to die from the flu and related viruses, including COVID-19, than children without neurologic disorders.
  - (7) There is no consensus of best practices for a person with cerebral palsy at the time of diagnosis or through the lifespan.

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
	of contracts) a program of research related to cerebra
19	palsy, including—
19 20	
	palsy, including—
20	palsy, including—  "(1) research on—
20 21	palsy, including—  "(1) research on—  "(A) the most promising avenues of cere-

1 "(C) the health care and societal costs of 2 cerebral palsy; "(2) public health surveillance; and 3 "(3) other research that the Director of the 4 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 lifelong effects 10 of cerebral palsy. 11 "(b) Technical Assistance.—The Secretary may 12 (directly or through grants or contracts) provide technical assistance to public and nonprofit private entities in fur-14 therance of research under this section. "(c) EVALUATIONS.—The Secretary shall (directly or 15 through grants or contracts) provide for the evaluation of 16 17 activities under subsection (a) in order to determine the 18 extent to which such activities have been effective, including evaluation of the effects of such activities on various 19 demographic populations. 20 21 AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there is authorized to be appropriated \$5,000,000 for each of fiscal years 2023 through

2028.".

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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 of the Eunice Kennedy Shriver National
8	Institute 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/NICHD 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.

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