

## Committee Print

(SHOWING THE TEXT OF H.R. 7406, AS FAVORABLY FORWARDED BY THE  
SUBCOMMITTEE ON HEALTH ON MARCH 12, 2024)

118TH CONGRESS  
2D SESSION

# H. R. 7406

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

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### IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 16, 2024

Mrs. RODGERS of Washington (for herself, Ms. DEGETTE, Mr. COLE, Ms. NORTON, Ms. DELAURO, and Mr. STAUBER) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## 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, training, and investigation related to Down syndrome, 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 “DeOndra Dixon IN-  
5 CLUDE Project Act of 2024”.

1 **SEC. 2. DOWN SYNDROME RESEARCH.**

2 Part A of title IV of the Public Health Service Act  
3 (42 U.S.C. 281 et seq.) is amended by adding at the end  
4 the following:

5 **“SEC. 404P. DOWN SYNDROM RESEARCH.**

6 “(a) IN GENERAL.—The Secretary, acting through  
7 the Office of the Director of NIH, and in consultation with  
8 other Federal agencies and partners, shall carry out a pro-  
9 gram of research, training, and investigation related to  
10 Down syndrome to be known as the ‘INvestigation of Co-  
11 occurring conditions across the Lifespan to Understand  
12 Down syndromE Project’ or the ‘INCLUDE Project’.

13 “(b) PROGRAM ELEMENTS.—The program under  
14 subsection (a) shall include research, training, and inves-  
15 tigation related to—

16 “(1) high-risk, high reward basic science studies  
17 of the effects of chromosome 21 on human develop-  
18 ment and health;

19 “(2) assembling and maintaining a large study  
20 population of individuals with Down syndrome;

21 “(3) expanding the number of clinical trials  
22 that are inclusive of, or expressly for, individuals  
23 with Down syndrome, including novel biomedical and  
24 pharmacological interventions and other therapies  
25 designed to promote or enhance activities of daily  
26 living;

1           “(4) the biological mechanisms in individuals  
2 with Down syndrome responsible for structural and  
3 functional anomalies in cells, tissues, and organs,  
4 cognitive and behavioral dysfunction, and stunted  
5 growth;

6           “(5) the identification of biomarkers for the de-  
7 tection of risk factors, diagnosis, and customized  
8 interventions and treatments for conditions co-occur-  
9 ring with Down syndrome;

10           “(6) why several co-occurring conditions, such  
11 as Alzheimer’s Disease and autoimmunity, are prev-  
12 alent in individuals with Down syndrome and how  
13 such conditions can be treated concurrently with  
14 Down syndrome; and

15           “(7) improving the quality of life of individuals  
16 with Down syndrome and their families.

17           “(c) COORDINATION; PRIORITIZING NONDUPLICA-  
18 TIVE RESEARCH.—The Secretary shall ensure that—

19           “(1) the programs and activities of the insti-  
20 tutes, centers, agencies, and offices of the National  
21 Institutes of Health relating to Down Syndrome and  
22 co-occurring conditions are coordinated, including  
23 through the Division of Program Coordination,  
24 Planning, and Strategic Initiatives under sections  
25 402(b)(7) and 402A(c); and

1           “(2) such institutes, centers, agencies, and of-  
2           fices prioritize, as appropriate, Down syndrome re-  
3           search that does not duplicate existing research ac-  
4           tivities of the National Institutes of Health.

5           “(d) TECHNICAL ASSISTANCE.—The Secretary shall  
6           provide technical assistance to grantees and other involved  
7           entities, as appropriate, for carrying out activities pursu-  
8           ant to this section.

9           “(e) BIENNIAL REPORTS TO CONGRESS.—

10           “(1) IN GENERAL.—The Secretary shall submit,  
11           on a biennial basis, to the Committee on Energy and  
12           Commerce and the Subcommittee on Labor, Health  
13           and Human Services, Education of the Committee  
14           on Appropriations of the House of Representatives  
15           and the Committee on Health, Education, Labor,  
16           and Pensions and the Subcommittee on Labor,  
17           Health and Human Services, Education, and Re-  
18           lated Agencies of the Committee on Appropriations  
19           of the Senate, a report that catalogs the research  
20           conducted or supported under this section.

21           “(2) CONTENTS.—Each report under para-  
22           graph (1) shall include—

23           “(A) identification of the institute, center,  
24           agency, office, or entity involved;

1           “(B) a statement of whether the research  
2           is or was being carried out directly by the insti-  
3           tute, center, agency, office, or entity or by mul-  
4           tiple institutes, centers, agencies, offices, or en-  
5           tities; and

6           “(C) identification of any resulting real  
7           world evidence that is or may be used for clin-  
8           ical research and medical care for patients with  
9           Down syndrome.

10          “(f) AUTHORIZATION OF APPROPRIATIONS.—

11           “(1) IN GENERAL.—To carry out this section,  
12           there is authorized to be appropriated \$250,000,000  
13           for each of fiscal years 2025 through 2029.

14           “(2) SUPPLEMENT, NOT SUPPLANT.—Funds  
15           appropriated to carry out this section shall be used  
16           to supplement, not supplant, other funds allocated  
17           by the National Institutes of Health for research  
18           and other activities relating to Down syndrome.”.