

# Union Calendar No. 419

118<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. R. 7406

**[Report No. 118-504]**

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

MAY 14, 2024

Additional sponsor: Mr. TRONE

MAY 14, 2024

Reported with an amendment, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in italic]

[For text of introduced bill, see copy of bill as introduced on February 16, 2024]

# **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”.*

6 **SEC. 2. DOWN SYNDROME RESEARCH.**

7        *Part A of title IV of the Public Health Service Act*  
8 *(42 U.S.C. 281 et seq.) is amended by adding at the end*  
9 *the following:*

10 **“SEC. 404P. DOWN SYNDROME RESEARCH.**

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

18        *“(b) PROGRAM ELEMENTS.—The program under sub-*  
19 *section (a) shall include research, training, and investiga-*  
20 *tion related to—*

21            *“(1) high-risk, high reward basic science studies*  
22            *of the effects of chromosome 21 on human development*  
23            *and health;*

24            *“(2) assembling and maintaining a large study*  
25            *population of individuals with Down syndrome;*

1           “(3) expanding the number of clinical trials that  
2           are inclusive of, or expressly for, individuals with  
3           Down syndrome, including novel biomedical and  
4           pharmacological interventions and other therapies de-  
5           signed to promote or enhance activities of daily liv-  
6           ing;

7           “(4) the biological mechanisms in individuals  
8           with Down syndrome responsible for structural and  
9           functional anomalies in cells, tissues, and organs, cog-  
10          nitive and behavioral dysfunction, and stunted  
11          growth;

12          “(5) the identification of biomarkers for the de-  
13          tection of risk factors, diagnosis, and customized  
14          interventions and treatments for conditions co-occur-  
15          ring with Down syndrome;

16          “(6) why several co-occurring conditions, such as  
17          Alzheimer’s Disease and autoimmunity, are prevalent  
18          in individuals with Down syndrome and how such  
19          conditions can be treated concurrently with Down  
20          syndrome; and

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

23          “(c) COORDINATION; PRIORITIZING NONDUPLICATIVE  
24          RESEARCH.—The Secretary shall ensure that—

1           “(1) *the programs and activities of the institutes,*  
2           *centers, agencies, and offices of the National Institutes*  
3           *of Health relating to Down Syndrome and co-occur-*  
4           *ring conditions are coordinated, including through*  
5           *the Division of Program Coordination, Planning, and*  
6           *Strategic Initiatives under sections 402(b)(7) and*  
7           *402A(c); and*

8           “(2) *such institutes, centers, agencies, and offices*  
9           *prioritize, as appropriate, Down syndrome research*  
10          *that does not duplicate existing research activities of*  
11          *the National Institutes of Health.*

12          “(d) *TECHNICAL ASSISTANCE.—The Secretary shall*  
13          *provide technical assistance to grantees and other involved*  
14          *entities, as appropriate, for carrying out activities pursu-*  
15          *ant to this section.*

16          “(e) *BIENNIAL REPORTS TO CONGRESS.—*

17                 “(1) *IN GENERAL.—The Secretary shall submit,*  
18                 *on a biennial basis, to the Committee on Energy and*  
19                 *Commerce and the Subcommittee on Labor, Health*  
20                 *and Human Services, Education of the Committee on*  
21                 *Appropriations of the House of Representatives and*  
22                 *the Committee on Health, Education, Labor, and*  
23                 *Pensions and the Subcommittee on Labor, Health and*  
24                 *Human Services, Education, and Related Agencies of*  
25                 *the Committee on Appropriations of the Senate, a re-*

1 *port that catalogs the research conducted or supported*  
2 *under this section.*

3 “(2) *CONTENTS.*—*Each report under paragraph*  
4 *(1) shall include—*

5 “(A) *identification of the institute, center,*  
6 *agency, office, or entity involved;*

7 “(B) *a statement of whether the research is*  
8 *or was being carried out directly by the institute,*  
9 *center, agency, office, or entity or by multiple in-*  
10 *stitutes, centers, agencies, offices, or entities; and*

11 “(C) *identification of any resulting real*  
12 *world evidence that is or may be used for clin-*  
13 *ical research and medical care for patients with*  
14 *Down syndrome.*

15 “(f) *AUTHORIZATION OF APPROPRIATIONS.*—

16 “(1) *IN GENERAL.*—*To carry out this section,*  
17 *there is authorized to be appropriated \$90,000,000 for*  
18 *each of fiscal years 2025 through 2029.*

19 “(2) *SUPPLEMENT, NOT SUPPLANT.*—*Funds ap-*  
20 *propriated to carry out this section shall be used to*  
21 *supplement, not supplant, other funds allocated by the*  
22 *National Institutes of Health for research and other*  
23 *activities relating to Down syndrome.”.*



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