

118TH CONGRESS
2D SESSION

H. R. 7406

AN ACT

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,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “DeOndra Dixon IN-
3 CLUDE Project Act of 2024”.

4 **SEC. 2. DOWN SYNDROME RESEARCH.**

5 Part A of title IV of the Public Health Service Act
6 (42 U.S.C. 281 et seq.) is amended by adding at the end
7 the following:

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

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

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

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

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

24 “(3) expanding the number of clinical trials
25 that are inclusive of, or expressly for, individuals
26 with Down syndrome, including novel biomedical and

1 pharmacological interventions and other therapies
2 designed to promote or enhance activities of daily
3 living;

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

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

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

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

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

22 “(1) the programs and activities of the insti-
23 tutes, centers, agencies, and offices of the National
24 Institutes of Health relating to Down Syndrome and
25 co-occurring conditions are coordinated, including

1 through the Division of Program Coordination,
2 Planning, and Strategic Initiatives under sections
3 402(b)(7) and 402A(c); and

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

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

12 “(e) BIENNIAL REPORTS TO CONGRESS.—

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

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

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

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

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

12 “(f) AUTHORIZATION OF APPROPRIATIONS.—

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

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

Passed the House of Representatives September 17,
2024.

Attest:

Clerk.

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