

119TH CONGRESS
2D SESSION

S. 1838

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 2026”.

4 **SEC. 2. DEONDRA DIXON INCLUDE PROJECT.**

5 Part B of title IV of the Public Health Service Act
6 (42 U.S.C. 284 et seq.) is amended by adding at the end
7 the following:

8 **“SEC. 409K. DOWN SYNDROME RESEARCH.**

9 “(a) IN GENERAL.—The Director of NIH shall carry
10 out a program of research, training, and investigation re-
11 lated to Down syndrome to be known as the ‘INvestigation
12 of Co-occurring conditions across the Lifespan to Under-
13 stand Down syndromE Project’ or the ‘INCLUDE
14 Project’.

15 “(b) PROGRAM ELEMENTS.—The program under
16 subsection (a) shall include—

17 “(1) high-risk, high-reward research on the ef-
18 fects of trisomy 21 on human development and
19 health;

20 “(2) promoting research for participants with
21 Down syndrome across the lifespan, including cohort
22 studies to facilitate improved understanding of
23 Down syndrome and co-occurring conditions and de-
24 velopment of new interventions;

25 “(3) expanding the number of clinical trials
26 that are inclusive of, or expressly for, participants

1 with Down syndrome, including novel biomedical and
2 pharmacological interventions and other therapies
3 designed to promote or enhance activities of daily
4 living;

5 “(4) research on the biological mechanisms in
6 individuals with Down syndrome pertaining to struc-
7 tural, functional, and behavioral anomalies and dys-
8 function as well as stunted growth;

9 “(5) supporting research to improve diagnosis
10 and treatment of conditions co-occurring with Down
11 syndrome, including the identification of biomarkers
12 related to risk factors, diagnosis, and clinical re-
13 search and therapeutics;

14 “(6) research on the causes of increased preva-
15 lence, and concurrent treatment, of co-occurring con-
16 ditions, such as Alzheimer’s disease and related de-
17 mentias and autoimmunity, in individuals with Down
18 syndrome; and

19 “(7) research, training, and investigation on im-
20 proving the quality of life of individuals with Down
21 syndrome and their families.

22 “(c) COORDINATION; PRIORITIZING NONDUPLICA-
23 TIVE RESEARCH.—The Director of NIH shall ensure
24 that—

1 “(1) the programs and activities of the insti-
2 tutes and centers of the National Institutes of
3 Health relating to Down syndrome and co-occurring
4 conditions are coordinated, including through the
5 Office of the Director of NIH and priority-setting
6 reviews conducted pursuant to section 402(b)(3);
7 and

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

12 “(d) CONSULTATION WITH STAKEHOLDERS.—In
13 carrying out activities under this section, the Director of
14 NIH shall, as appropriate and to the maximum extent fea-
15 sible, consult with relevant stakeholders, including patient
16 advocates, to ensure that such activities take into consid-
17 eration the needs of individuals with Down syndrome.

18 “(e) BIENNIAL REPORTS TO CONGRESS.—

19 “(1) IN GENERAL.—The Director of NIH shall
20 submit, on a biennial basis, to the Committee on
21 Energy and Commerce and the Subcommittee on
22 Labor, Health and Human Services, Education, and
23 Related Agencies of the Committee on Appropria-
24 tions of the House of Representatives and the Com-
25 mittee on Health, Education, Labor, and Pensions

1 and the Subcommittee on Labor, Health and
 2 Human Services, Education, and Related Agencies
 3 of the Committee on Appropriations of the Senate,
 4 a report that catalogs the research conducted or
 5 supported under this section.

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

8 “(A) identification of the institute or cen-
 9 ter involved;

10 “(B) a statement of whether the research
 11 is or was being carried out directly by such in-
 12 stitute or center or by multiple institutes and
 13 centers; and

14 “(C) identification of any resulting real-
 15 world evidence that is or may be used for clin-
 16 ical research and medical care for patients with
 17 Down syndrome.”.

Passed the Senate August 6, 2026.

Attest:

Secretary.

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