

119TH CONGRESS
1ST SESSION

H. R. 1750

To amend the Public Health Service Act to provide for greater investments in research on rare diseases and conditions disproportionately affecting minority populations, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 27, 2025

Ms. STRICKLAND introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committees on Ways and Means, and Natural Resources, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To amend the Public Health Service Act to provide for greater investments in research on rare diseases and conditions disproportionately affecting minority populations, 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 “Health Equity and
5 Rare Disease Act of 2025” or the “HEARD Act of 2025”.

1 **SEC. 2. NIH EXPANSION, INTENSIFICATION, AND COORDI-**
2 **NATION OF RESEARCH ON RARE DISEASES**
3 **HEALTH EQUITY.**

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

7 **“SEC. 409K. RARE DISEASES HEALTH EQUITY.**

8 “(a) EXPANSION, INTENSIFICATION, AND COORDINA-
9 TION OF ACTIVITIES.—

10 “(1) IN GENERAL.—The Director of NIH shall
11 expand, intensify, and coordinate research and other
12 activities of the National Institutes of Health with
13 respect to rare diseases health equity.

14 “(2) ALLOCATIONS BY DIRECTOR OF NIH.—
15 With respect to amounts appropriated to carry out
16 this section for a fiscal year, the Director of NIH
17 shall allocate the amounts among the national re-
18 search institutes that are carrying out paragraph
19 (1).

20 “(b) COORDINATING COMMITTEE.—

21 “(1) IN GENERAL.—The Secretary shall main-
22 tain a coordinating committee with respect to rare
23 diseases health equity (referred to in this section as
24 the ‘Coordinating Committee’) to coordinate activi-
25 ties across the National Institutes and with other

1 Federal health programs and activities relating to
2 rare diseases health equity.

3 “(2) COMPOSITION.—The Coordinating Com-
4 mittee shall be composed of—

5 “(A) the directors (or their designees) of
6 each of the national research institutes involved
7 in research with respect to rare diseases and
8 minority health or health equity; and

9 “(B) representatives of all other Federal
10 departments and agencies whose programs in-
11 volve health functions or responsibilities rel-
12 evant to such rare diseases, including the Cen-
13 ters for Disease Control and Prevention and the
14 Food and Drug Administration.

15 “(3) CHAIR.—

16 “(A) IN GENERAL.—With respect to rare
17 diseases health equity, the Chair of the Coordi-
18 nating Committee shall serve as the principal
19 advisor to the Secretary, the Assistant Sec-
20 retary for Health, and the Director of NIH,
21 and shall provide advice to the Director of the
22 Centers for Disease Control and Prevention, the
23 Commissioner of Food and Drugs, and other
24 relevant agencies.

1 “(B) DIRECTOR OF NIH.—The Chair of
2 the Coordinating Committee shall be directly re-
3 sponsible to the Director of NIH.

4 “(c) PLAN FOR NIH ACTIVITIES.—

5 “(1) IN GENERAL.—Not later than 1 year after
6 the date of the enactment of this section, the Coordi-
7 nating Committee shall develop a plan for con-
8 ducting and supporting research and education on
9 rare diseases health equity, and rare diseases or con-
10 ditions in minority populations, through the national
11 research institutes. The Coordinating Committee
12 shall periodically review and revise the plan. The
13 plan shall—

14 “(A) provide for a broad range of research
15 and education activities relating to biomedical,
16 psychosocial, and rehabilitative issues, including
17 studies of the disproportionate impact of such
18 diseases or conditions on minority populations;

19 “(B) identify priorities among the pro-
20 grams and activities of the National Institutes
21 of Health regarding such diseases or conditions;
22 and

23 “(C) reflect input from a broad range of
24 scientists, patients, and advocacy groups.

1 “(2) CERTAIN ELEMENTS OF PLAN.—The plan
2 under paragraph (1) shall, with respect to rare dis-
3 eases or conditions in minority populations, provide
4 for the following as appropriate:

5 “(A) Research to determine the reasons
6 underlying the incidence and prevalence of the
7 diseases or conditions, including among sub-
8 populations.

9 “(B) Basic research concerning the eti-
10 ology and causes of the diseases or conditions.

11 “(C) Epidemiological studies to address
12 the frequency and natural history of the dis-
13 eases or conditions, including any differences
14 among the sexes and among racial and ethnic
15 groups.

16 “(D) The development of improved screen-
17 ing techniques.

18 “(E) Clinical research for the development
19 and evaluation of new treatments, including
20 new biological agents.

21 “(F) Information and education programs
22 for health care professionals and the public.

23 “(3) IMPLEMENTATION OF PLAN.—The Direc-
24 tor of NIH shall ensure that programs and activities
25 of the National Institutes of Health regarding rare

1 diseases or conditions in minority populations are
 2 implemented in accordance with the plan under
 3 paragraph (1).

4 “(d) DEFINITIONS.—In this section:

5 “(1) The term ‘minority’ has the meaning given
 6 such term in section 464z–3.

7 “(2) The term ‘rare disease or condition’ has
 8 the meaning given such term in section 526 of the
 9 Federal Food, Drug, and Cosmetic Act (21 U.S.C.
 10 360bb).”.

11 **SEC. 3. COLLABORATIVE COMPREHENSIVE PLAN TO AD-**
 12 **DRESS RARE DISEASES AND CONDITIONS IN**
 13 **MINORITY POPULATIONS.**

14 Subpart 20 of part C of title IV of the Public Health
 15 Service Act (42 U.S.C. 285t et seq.) is amended by adding
 16 at the end the following:

17 **“SEC. 464z–7. COLLABORATIVE COMPREHENSIVE PLAN TO**
 18 **ADDRESS RARE DISEASES AND CONDITIONS**
 19 **IN MINORITY POPULATIONS.**

20 “Not later than 180 days after the date of enactment
 21 of this section, the Director of NIH, the Director of the
 22 Institute, the Director of the National Center for Advanc-
 23 ing Translational Sciences, the Director of the National
 24 Heart, Lung, and Blood Institute, and the directors of the
 25 other agencies of the National Institutes of Health in col-

1 laboration (and in consultation with the advisory council
2 for the Institute) shall—

3 “(1) develop a comprehensive Federal plan to
4 address rare diseases and conditions in minority
5 populations (as those terms are defined in section
6 409K), including a strategy to increase diversity in
7 genetic programs at the program for Therapeutics
8 for Rare and Neglected Diseases at the National In-
9 stitutes of Health;

10 “(2) conduct or support through grants or co-
11 operative agreements basic, clinical, and
12 translational research on rare diseases and condi-
13 tions in minority populations, including research
14 on—

15 “(A) early detection, diagnosis, and treat-
16 ment of such diseases and conditions in such
17 populations; and

18 “(B) improving the quality of life for indi-
19 viduals with rare diseases or conditions and
20 their families;

21 “(3) conduct or support clinical training pro-
22 grams for physicians and other health care practi-
23 tioners with respect to detecting, diagnosing, and
24 treating such diseases and conditions in such popu-
25 lations; and

1 “(4) develop guidance for increasing participa-
2 tion of health professionals who are members of mi-
3 nority groups (as defined in section 464z–3) in re-
4 search conducted or supported by the National Insti-
5 tutes of Health on such diseases and conditions in
6 such populations.”.

7 **SEC. 4. GRANTS TO COLLECT AND ANALYZE DATA ON RARE**
8 **DISEASES AND CONDITIONS IN MINORITY**
9 **POPULATIONS.**

10 Section 1707(b) of the Public Health Service Act (42
11 U.S.C. 300u–6(b)) is amended by adding at the end the
12 following:

13 “(11) In coordination with the Director of the
14 Centers for Disease Control and Prevention, award
15 grants to public and private nonprofit entities to—

16 “(A) collect, analyze, and report data on
17 rare diseases and conditions in minority popu-
18 lations, including on epidemiological data with
19 respect to incidence of such diseases and condi-
20 tions in such populations;

21 “(B) conduct outreach and engagement ac-
22 tivities with the minority populations impacted
23 by such rare diseases and conditions by—

24 “(i) improving health literacy with re-
25 spect to rare diseases and conditions;

1 “(ii) disseminating information on
2 health and community services related to
3 rare diseases and conditions; and

4 “(iii) providing information regarding
5 the maintenance of rare diseases and con-
6 ditions.

7 “(12) Submit to Congress, on a biannual basis
8 (beginning not later than 2 years after the date of
9 the enactment of the HEARD Act of 2025), a re-
10 port describing the activities carried out pursuant to
11 paragraph (11).”.

12 **SEC. 5. PHYSICIAN TRAINING PROGRAMS WITH RESPECT**
13 **TO RARE DISEASES.**

14 Subpart II of part C of title VII of the Public Health
15 Service Act is amended by adding at the end the following:

16 **“SEC. 749C. PHYSICIAN TRAINING PROGRAMS WITH RE-**
17 **SPECT TO RARE DISEASES.**

18 “(a) IN GENERAL.—The Secretary shall establish a
19 program to award grants to accredited schools of
20 allopathic medicine, osteopathic medicine, and nursing,
21 and other health professional training programs for the
22 training of health care professionals—

23 “(1) to improve the provision of care to individ-
24 uals who have rare diseases or conditions (as defined

1 in section 526 of the Federal Food, Drug, and Cos-
2 metic Act (21 U.S.C. 360bb));

3 “(2) to improve the provision of care to such in-
4 dividuals via telehealth; and

5 “(3) to conduct research relevant to rare dis-
6 eases and conditions.

7 “(b) ELIGIBILITY.—To be eligible for a grant under
8 subsection (a), an entity described in such subsection shall
9 submit to the Secretary an application at such time, in
10 such manner, and containing such information as the Sec-
11 retary may require.

12 “(c) REPORTING REQUIREMENTS.—

13 “(1) PERIODIC REPORTS.—Each entity awarded
14 a grant under this section shall periodically submit
15 to the Secretary a report on the status of activities
16 conducted using the grant, including a description of
17 the impact of such training on patient outcomes, as
18 applicable.

19 “(2) REPORT TO CONGRESS.—Not later than 2
20 years after the date of enactment of this section, the
21 Secretary shall submit a report to Congress on the
22 activities conducted using grants under subsection
23 (a) and any best practices identified and dissemi-
24 nated under subsection (d).

1 “(d) BEST PRACTICES.—The Secretary may identify
2 and disseminate best practices for the training described
3 in subsection (a).

4 **“SEC. 749D. HEALTH PROFESSIONALS EDUCATION ON RARE**
5 **DISEASES AND CONDITIONS IN MINORITY**
6 **POPULATIONS.**

7 “(a) IN GENERAL.—The Secretary may award
8 grants, cooperative agreements, and contracts to accredited
9 schools of medicine and nursing, and other health professional
10 training programs, for the development and implementation
11 of programs to provide education and training to health care
12 professionals on the causes and effects
13 of rare diseases and conditions in minority populations.

14 “(b) DEFINITIONS.—In this section:

15 “(1) The term ‘minority’ has the meaning given
16 such term in section 464z–3.

17 “(2) The term ‘rare disease or condition’ has
18 the meaning given such term in section 526 of the
19 Federal Food, Drug, and Cosmetic Act (21 U.S.C.
20 360bb).

21 **“SEC. 749E. MENTORING PROGRAM FOR HEALTH CARE**
22 **PROFESSIONALS SEEKING TO WORK IN RARE**
23 **DISEASES AND CONDITIONS.**

24 “The Secretary, acting through the Administrator of
25 the Health Resources and Services Administration, may

1 award grants, contracts, or cooperative agreements to
2 public and nonprofit private entities (including Tribal enti-
3 ties) for the establishment of a mentoring program for
4 health care professionals seeking to treat patients with
5 rare diseases and conditions.

6 **“SEC. 749F. SCHOLARSHIP AND LOAN REPAYMENT PRO-**
7 **GRAM FOR PHYSICIANS AND GENETIC COUN-**
8 **SELORS SERVING POPULATIONS WITH RARE**
9 **DISEASES AND CONDITIONS.**

10 “(a) LOAN REPAYMENT PROGRAM.—

11 “(1) IN GENERAL.—The Secretary shall estab-
12 lish a program of entering into contracts with eligi-
13 ble individuals under which the individuals agree to
14 serve as health care professionals serving popu-
15 lations with rare diseases or conditions in consider-
16 ation of the Federal Government agreeing to pay,
17 for each year of such service, up to \$50,000 (plus
18 an amount determined by the Secretary on an an-
19 nual basis to reflect inflation) of the principal and
20 interest of the educational loans of such individuals.

21 “(2) DETERMINATION OF AMOUNT.—In making
22 a determination of the amount to pay for a year of
23 such service by an individual, the Secretary shall
24 consider the extent to which each such determina-
25 tion—

1 “(A) affects the ability of the Secretary to
2 maximize the number of contracts that can be
3 provided under the program from the amounts
4 appropriated for such contracts;

5 “(B) provides an incentive to serve as
6 health care professionals serving populations
7 with rare diseases or conditions; and

8 “(C) provides an incentive with respect to
9 the health professional involved to remain serv-
10 ing populations with rare diseases or conditions,
11 including after the completion of the period of
12 obligated service under the program.

13 “(3) ELIGIBLE INDIVIDUALS.—In this sub-
14 section, the term ‘eligible individual’ means an indi-
15 vidual who is enrolled or accepted for enrollment as
16 a full-time or part-time student in a school of medi-
17 cine.

18 “(4) APPLICABILITY OF CERTAIN PROVI-
19 SIONS.—With respect to the National Health Service
20 Corps Loan Repayment Program established in sub-
21 part III of part D of title III of this Act, the provi-
22 sions of such subpart shall, except as inconsistent
23 with paragraph (1), apply to the program estab-
24 lished in this section in the same manner and to the

1 same extent as such provisions apply to the National
2 Health Service Corps Loan Repayment Program.

3 “(b) SCHOLARSHIP PROGRAM.—

4 “(1) IN GENERAL.—The Secretary shall carry
5 out a program of entering into contracts with eligi-
6 ble individuals under which each such individual
7 agrees to serve, for a period of not less than 5 years,
8 as a health care professional primarily serving popu-
9 lations with rare diseases or conditions, in consider-
10 ation of the Federal Government agreeing to provide
11 to the individual a scholarship for attendance at a
12 school of medicine.

13 “(2) ELIGIBLE INDIVIDUALS.—In this sub-
14 section, the term ‘eligible individual’ means an indi-
15 vidual who is enrolled or accepted for enrollment as
16 a full-time or part-time student in a school of medi-
17 cine.

18 “(3) APPLICABILITY OF CERTAIN PROVI-
19 SIONS.—The provisions of subpart III of part D of
20 title III shall, except as inconsistent with this sec-
21 tion, apply to the program established in paragraph
22 (1) in the same manner and to the same extent as
23 such provisions apply to the National Health Service
24 Corps Scholarship Program established in such sub-
25 part.”.

1 **SEC. 6. INCREASING MINORITY REPRESENTATION IN RE-**
2 **SEARCH ON RARE DISEASES AND CONDI-**
3 **TIONS.**

4 Part G of title IV of the Public Health Service Act
5 (42 U.S.C. 288 et seq.) is amended by adding at the end
6 the following:

7 **“SEC. 487E. INCREASING MINORITY REPRESENTATION IN**
8 **RESEARCH ON RARE DISEASES AND CONDI-**
9 **TIONS.**

10 “(a) GRANT PROGRAM.—In carrying out section 487,
11 the Secretary may award grants to eligible entities in-
12 volved in research on rare diseases and minority health
13 to establish programs to increase the recruitment and re-
14 tention of members of minority groups to conduct research
15 in matters relating to the cause, diagnosis, prevention, and
16 treatment of rare diseases or conditions, including by ex-
17 panding the number of internships and mentoring oppor-
18 tunities.

19 “(b) ELIGIBLE ENTITIES.—In subsection (a), the
20 term ‘eligible entities’ means accredited schools of
21 allopathic medicine, osteopathic medicine, and nursing,
22 and other health professional training programs.”.

1 **SEC. 7. REPORT TO CONGRESS ON FEDERAL EFFORTS ON**
2 **RARE DISEASES AND CONDITIONS IN MINOR-**
3 **ITY POPULATIONS.**

4 Not later than 2 years after the date of enactment
5 of this Act, the Secretary of Health and Human Services,
6 acting through the Director of the National Institutes of
7 Health and in consultation with the Director of the Cen-
8 ters for Disease Control and Prevention, shall submit to
9 Congress—

10 (1) a report on research and public health ac-
11 tivities carried out by the Federal Government with
12 respect to rare diseases or conditions in minority
13 populations (as those terms are defined in section
14 409K of the Public Health Service Act, as added by
15 section 2 of this Act);

16 (2) a comprehensive list of known rare diseases
17 and conditions that impact minority populations
18 heavily or disproportionately; and

19 (3) an analysis of data gaps with respect to
20 rare diseases and conditions and the effect of such
21 diseases and conditions on minority populations.

1 **SEC. 8. RESEARCH AND AWARENESS CAMPAIGNS WITH RE-**
2 **SPECT TO RARE DISEASES AND CONDITIONS**
3 **IN MINORITY POPULATIONS.**

4 Part B of title III of the Public Health Service Act
5 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
6 tion 317V (42 U.S.C. 247b–24) the following:

7 **“SEC. 317W. RESEARCH AND AWARENESS CAMPAIGNS WITH**
8 **RESPECT TO RARE DISEASES AND CONDI-**
9 **TIONS IN MINORITY POPULATIONS.**

10 “(a) RESEARCH.—The Secretary, acting through the
11 Director of the Centers for Disease Control and Preven-
12 tion, shall conduct or support research and carry out pub-
13 lic health awareness campaigns with respect to rare dis-
14 eases and conditions in minority populations (as defined
15 in section 409K).

16 “(b) AWARENESS CAMPAIGN.—The Secretary shall,
17 directly or through grants or contracts, establish a public
18 education program in cooperation with existing national
19 public awareness campaigns to increase awareness about
20 rare diseases and conditions in minority populations
21 through culturally and linguistically appropriate informa-
22 tion campaigns about prevention and management of rare
23 diseases and conditions.”.

1 **SEC. 9. FDA SURVEY AND REPORT ON CLINICAL TRIAL DI-**
2 **VERSITY.**

3 Not later than 2 years after the date of enactment
4 of this Act, the Secretary of Health and Human Services,
5 acting through the Commissioner of Food and Drugs,
6 shall—

7 (1) conduct a survey of policies and programs
8 of the Food and Drug Administration to support an
9 increase the availability of clinical trial data on mi-
10 nority populations, with an emphasis on minority
11 populations with rare diseases and conditions; and

12 (2) submit to Congress a report containing—

13 (A) the findings of such survey;

14 (B) the Secretary's recommendations for
15 statutory or regulatory changes to increase the
16 availability of such data;

17 (C) the Secretary's recommendations for
18 strategies to encourage drug manufacturers to
19 address racial equity and inclusion in research
20 and development of treatments of rare diseases
21 or conditions that disproportionately impact mi-
22 nority populations; and

23 (D) the Secretary's recommendations for
24 strategies to address research and development
25 of treatments of rare diseases or conditions that
26 disproportionately impact minority populations.

1 **SEC. 10. TRIBAL EPIDEMIOLOGY CENTER GRANT PRO-**
2 **GRAM.**

3 Title II of the Indian Health Care Improvement Act
4 (25 U.S.C. 1621 et seq.) is amended by adding at the end
5 the following:

6 **“SEC. 227. TRIBAL EPIDEMIOLOGY CENTER GRANT PRO-**
7 **GRAM.**

8 “(a) IN GENERAL.—The Secretary, acting through
9 the Service, shall award grants to Tribal Epidemiology
10 Centers and Tribal and Urban Indian Health Centers to
11 support clinically and culturally appropriate research and
12 other activities with respect to rare diseases and condi-
13 tions in Native American or Tribal communities.

14 “(b) PERMISSIBLE ACTIVITIES.—The activities fund-
15 ed through a grant under subsection (a) may include co-
16 ordination of data collection on the prevention, diagnosis,
17 treatment, and care of rare diseases and conditions by
18 health care professionals serving American Indian and
19 Alaska Native populations.”.

20 **SEC. 11. MEDICARE REVIEW AND REPORT.**

21 Not later than 180 days after the date of enactment
22 of this Act, the Secretary of Health and Human Service
23 shall conduct a review of and submit to Congress a report
24 on the following:

25 (1) Regulatory barriers under the Medicare pro-
26 gram under title XVIII of the Social Security Act

1 (42 U.S.C. 1395 et seq.) that inhibit access to the
2 treatment of rare diseases for Medicare beneficiaries
3 of color, including barriers that inhibit health care
4 providers from improving care related to such dis-
5 eases for such beneficiaries.

6 (2) Requirements relating to the furnishing of
7 telehealth services under such title insofar as such
8 services relate to the treatment of rare diseases.

9 Such report shall include any recommendations deter-
10 mined appropriate by the Secretary based on such review.

○