

119TH CONGRESS
1ST SESSION

H. R. 5536

To direct the Secretary of Health and Human Services to carry out a National Headache Disorders Initiative, to establish an Advisory Council on Headache Disorders Research, Care, and Services, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 19, 2025

Mrs. TRAHAN (for herself, Ms. BUDZINSKI, Mr. MOULTON, Ms. KELLY of Illinois, and Mrs. FOUSHEE) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To direct the Secretary of Health and Human Services to carry out a National Headache Disorders Initiative, to establish an Advisory Council on Headache Disorders Research, Care, and Services, 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 “Headache Education,
5 Access, Diagnosis, and Care Health Equity Act” or the
6 “HEADACHE Act”.

1 **SEC. 2. DEFINITION.**

2 In this Act:

3 (1) HEADACHE DISORDER.—

4 (A) IN GENERAL.—The term “headache
5 disorder” means a primary or secondary med-
6 ical condition for which headache is a principal
7 symptom.

8 (B) INCLUSION OF CERTAIN MEDICAL CON-
9 DITIONS.—The medical conditions referred to in
10 subparagraph (A) include migraine, cluster
11 headache, tension-type headache, spinal cere-
12 brospinal fluid (CSF) leak, idiopathic
13 intracranial hypertension, new daily persistent
14 headache, headache secondary to long COVID,
15 orofacial pain disorders, post-traumatic head-
16 ache secondary to traumatic brain injury, and
17 headache disorders affecting vulnerable popu-
18 lations such as children, pregnant women, and
19 older adults.

20 (2) SECRETARY.—The term “Secretary” means
21 the Secretary of Health and Human Services, except
22 as otherwise specifically provided.

23 **SEC. 3. NATIONAL HEADACHE DISORDERS INITIATIVE.**

24 (a) IN GENERAL.—The Secretary shall carry out an
25 initiative, to be known as the National Headache Dis-
26 orders Initiative (in this section referred to as the

1 “NHDI”), in accordance with the requirements of this
2 section.

3 (b) COMPONENTS.—In carrying out the NHDI, the
4 Secretary shall—

5 (1) establish and implement a comprehensive
6 program to address the medical, societal, and eco-
7 nomic impacts of headache disorders;

8 (2) take such actions as may be necessary to in-
9 crease the clinical and research workforce focused on
10 the care of patients with headache disorders;

11 (3) coordinate with other Federal initiatives
12 with missions that overlap with NHDI, including the
13 Helping End Addiction Long-Term (HEAL) Initia-
14 tive, the NIH Pain Consortium, the Interagency
15 Pain Research Coordinating Committee, and the
16 Centers of Excellence in Pain Education;

17 (4) ensure that Federal resources available to
18 support headache disorders research and services
19 across all agencies are commensurate with the high
20 disease burden exacted by these conditions;

21 (5) ensure prioritization of fundamental,
22 translational, and clinical research to improve the
23 speed, accuracy, and cost of diagnosis of headache
24 disorders, and the development of innovative thera-

1 peutics to prevent and ameliorate the symptoms of
2 headache disorders;

3 (6) improve protocols for the diagnosis and the
4 coordination of care of headache disorders, including
5 care pathways that address comorbid medical condi-
6 tions;

7 (7) enhance the epidemiological database of
8 headache disorders to ensure comprehensive and in-
9 clusive data collection that improves clinical care, re-
10 search, and public health efforts while addressing
11 disparities in diagnosis, treatment, and access to
12 care;

13 (8) enhance social research of headache dis-
14 orders and coordinate public awareness campaigns
15 to reduce stigma associated with such disorders; and

16 (9) coordinate with international bodies to inte-
17 grate and inform global efforts surrounding head-
18 ache disorders.

19 (c) DUTIES.—The Secretary shall—

20 (1) oversee the establishment and updating of
21 the NHDI; and

22 (2) evaluate all Federal programs related to
23 headache disorders, including budget requests and
24 approvals.

1 **SEC. 4. ADVISORY COUNCIL ON HEADACHE DISORDERS RE-**
2 **SEARCH, CARE, AND SERVICES.**

3 (a) ESTABLISHMENT.—The Secretary shall establish
4 and maintain an Advisory Council on Headache Disorders
5 Research, Care, and Services (referred to in this section
6 as the “Advisory Council”) for the purpose of advising the
7 Secretary on matters relating to headache disorders.

8 (b) MEMBERSHIP.—

9 (1) FEDERAL MEMBERS.—The Advisory Coun-
10 cil shall be comprised of experts, to be appointed by
11 the Secretary, who collectively are from various
12 backgrounds and perspectives, including at least one
13 member from each of the following:

14 (A) The National Institutes of Health.

15 (B) The Office of Research on Women’s
16 Health.

17 (C) The Food and Drug Administration.

18 (D) The Centers for Medicare & Medicaid
19 Services.

20 (E) The Indian Health Service.

21 (F) The Department of Veterans Affairs.

22 (G) The Department of Defense.

23 (H) The Centers for Disease Control and
24 Prevention.

25 (I) The Agency for Healthcare Research
26 and Quality.

1 (J) The Patient-Centered Outcomes Re-
2 search Institute.

3 (K) The Advanced Research Projects
4 Agency for Health.

5 (L) The National Center for Complemen-
6 tary and Integrative Health.

7 (M) The Department of Education.

8 (N) Other Federal departments and agen-
9 cies.

10 (2) NON-FEDERAL MEMBERS.—In addition to
11 the members specified in paragraph (1), the Advi-
12 sory Council shall include 12 members, to be ap-
13 pointed by the Secretary, who shall include rep-
14 resentatives of minority communities, communities
15 disproportionately affected by headache disorders,
16 and communities underrepresented in headache dis-
17 orders research, who shall each be from outside the
18 Federal Government, and who shall include the fol-
19 lowing:

20 (A) Two individuals who are patient advo-
21 cates, including one individual who is living
22 with migraine and one individual with a non-mi-
23 graine headache disorder.

24 (B) An individual who is a caregiver of a
25 child or adolescent with a headache disorder.

1 (C) Individuals who are healthcare pro-
2 viders specializing in headache (those with a pa-
3 tient base where greater than 80 percent are
4 headache patients), including—

5 (i) at least one individual who is Doc-
6 tor of Medicine or Doctor of Osteopathic
7 Medicine;

8 (ii) at least one individual who is an
9 Advanced Practice Provider;

10 (iii) at least one individual who is a
11 behavioral health specialist;

12 (iv) at least one individual who is an
13 orofacial pain specialist;

14 (v) at least one individual who is a
15 front-line provider (such as a primary care
16 physician or emergency care provider); and

17 (vi) at least one individual who is a
18 researcher with expertise in headache dis-
19 orders.

20 (D) At least one individual who is a rep-
21 resentative of a non-profit patient advocacy or-
22 ganization focused exclusively on headache dis-
23 orders.

24 (c) MEETINGS.—

1 (1) FREQUENCY.—The Advisory Council shall
2 meet—

3 (A) at least once each quarter during the
4 2-year period beginning on the date on which
5 the Advisory Council is established; and

6 (B) at the Secretary’s discretion after the
7 expiration of such period.

8 (2) ANNUAL RESEARCH MEETING.—Not later
9 than two years after the date of enactment of this
10 Act, and every year thereafter, the Advisory Council
11 shall convene a meeting of Federal and non-Federal
12 organizations to discuss headache disorders research.

13 (d) TERMINATION.—The Advisory Council shall ter-
14 minate on the sunset date specified in section 7.

15 **SEC. 5. DATA SHARING.**

16 (a) IN GENERAL.—The heads of Federal agencies,
17 within and outside the Department of Health and Human
18 Services, that have data relating to headache disorders
19 shall, at the request of the Secretary, share such data with
20 the Secretary to enable the Secretary to complete the re-
21 port required under section 6.

22 (b) INCLUDED DATA.—The data-sharing requirement
23 under subsection (a) includes standardized data collection
24 across agencies and integration with non-Federal sources,

1 such as electronic health records, patient registries, and
2 population health surveys.

3 **SEC. 6. ANNUAL REPORT TO CONGRESS.**

4 (a) IN GENERAL.—The Secretary shall submit to
5 Congress an annual report containing information relating
6 to headache disorders, as specified in subsection (b).

7 (b) CONTENTS.—The annual report shall include the
8 following:

9 (1) An evaluation of all federally funded efforts
10 relating to headache disorders research, clinical care,
11 and other treatment programs and their outcomes.

12 (2) An evaluation of program performance, mis-
13 sion, and purpose, including data on headache dis-
14 parities across racial, ethnic, socioeconomic, and geo-
15 graphic lines.

16 (3) Recommendations for priority actions, in-
17 cluding—

18 (A) reducing the financial impact of head-
19 ache disorders on Medicare and other federally
20 funded programs;

21 (B) improving health outcomes by updat-
22 ing diagnostic protocols, improving access to
23 care, and advancing therapeutic research; and

24 (C) strategies to increase public awareness
25 and reduce stigma.

1 (4) An annually updated national plan that ad-
2 dresses both short-term and long-term objectives for
3 addressing headache disorders.

4 **SEC. 7. SUNSET DATE.**

5 This Act shall cease to be effective on the date that
6 is 5 year after the date of enactment of this Act.

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