

Calendar No. 526

119TH CONGRESS
2D SESSION**S. 494**

To establish a national plan to coordinate research on epilepsy, and for
other purposes.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 10, 2025

Mr. SCHMITT (for himself, Ms. KLOBUCHAR, Mr. BOOZMAN, Ms. HASSAN, Mr. HUSTED, Mr. MARKEY, Mr. BOOKER, Ms. ERNST, Mr. PADILLA, Mrs. CAPITO, Mrs. SHAHEEN, Mr. COONS, Mr. WARNOCK, Mr. KAINE, Mr. WARNER, Ms. ALSOBROOKS, Mr. HEINRICH, Mr. SCHIFF, Mrs. GILLIBRAND, Ms. COLLINS, Mr. JUSTICE, Ms. BLUNT ROCHESTER, Ms. DUCKWORTH, Mr. KENNEDY, Mr. MARSHALL, Mr. DURBIN, Ms. ROSEN, and Mr. BENNET) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

JULY 28, 2026

Reported by Mr. CASSIDY, with an amendment

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

A BILL

To establish a national plan to coordinate research on
epilepsy, 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 “National Plan for Epi-
3 lepsy Act”.

4 **SEC. 2. FINDINGS.**

5 Congress finds as follows:

6 (1) Epilepsy is a brain disorder that causes re-
7 curring and unprovoked seizures and affects people
8 of all ages, affecting nearly 3,000,000 adults and
9 456,000 children in the United States.

10 (2) Epilepsy and seizures can develop in any
11 person at any age. One in 26 people will develop a
12 form of epilepsy in their lifetime, with people from
13 all demographic groups and walks of life being im-
14 pacted.

15 (3) In approximately half of all cases of epi-
16 lepsy, the underlying cause of the disease is un-
17 known.

18 (4) Epilepsy is a spectrum disease comprised of
19 many diagnoses and an ever-growing number of rare
20 epilepsies. There are many different types of sei-
21 zures and varying levels of seizure control.

22 (5) Over 30 percent of people with epilepsy live
23 with uncontrolled seizures.

24 (6) Individuals with epilepsy have a 3-times
25 higher risk of early death than the general popu-

1 lation and that risk is even higher for individuals
2 with uncontrolled seizures.

3 ~~(7) Thirty-two percent of adults with epilepsy~~
4 ~~are unable to work.~~

5 (8) Fifty-three percent of individuals with un-
6 controlled seizures live in households earning less
7 than \$25,000 per year.

8 (9) Health care costs associated with epilepsy
9 and seizures exceed \$54,000,000,000 per year in the
10 United States.

11 **SEC. 3. ESTABLISHING A NATIONAL PLAN FOR EPILEPSY.**

12 Part B of title III of the Public Health Service Act
13 ~~(42 U.S.C. 243 et seq.)~~ is amended by adding at the end
14 the following:

15 **~~“SEC. 320C. PROGRAMS RELATING TO EPILEPSY.~~**

16 ~~“(a) NATIONAL PLAN FOR EPILEPSY.—~~

17 ~~“(1) IN GENERAL.—The Secretary shall carry~~
18 ~~out a national project, to be known as the ‘National~~
19 ~~Plan for Epilepsy’ (referred to in this section as the~~
20 ~~‘National Plan’), to prevent, diagnose, treat, and~~
21 ~~cure epilepsy.~~

22 ~~“(2) ACTIVITIES.—In carrying out the National~~
23 ~~Plan, the Secretary shall—~~

1 “(A) establish, maintain, and periodically
2 update an integrated national plan to prevent,
3 diagnose, treat, and cure epilepsy;

4 “(B) provide information, including an es-
5 timate of the level of Federal investment in pre-
6 venting, diagnosing, treating, and curing epi-
7 lepsy;

8 “(C) coordinate research and services re-
9 lated to epilepsy, across all Federal agencies;

10 “(D) encourage the development of safe
11 and effective treatments, strategies, and other
12 approaches to prevent, diagnose, treat, and cure
13 epilepsy or to enhance functioning and improve
14 quality of life for individuals with epilepsy and
15 their caregivers;

16 “(E) improve the—

17 “(i) early diagnosis of epilepsy; and

18 “(ii) coordination of the care and
19 treatment of individuals living with epi-
20 lepsy;

21 “(F) review the impact of epilepsy on the
22 physical, mental, and social health of individ-
23 uals living with epilepsy and their caregivers;

1 “(G) solicit public comments and consider
2 consensus recommendations from collaborations
3 in the epilepsy community;

4 “(H) carry out an annual assessment on
5 progress of the activities described in this sub-
6 section;

7 “(I) coordinate with international bodies;
8 to the degree possible, to integrate and inform
9 the global mission to prevent, diagnose, treat,
10 and cure epilepsy; and

11 “(J) carry out other such activities as the
12 Secretary determines appropriate.

13 “(b) ANNUAL ASSESSMENT.—Not later than 2 years
14 after the date of enactment of the National Plan for Epi-
15 lepsy Act, and annually thereafter, the Secretary shall
16 carry out an assessment of the Nation’s progress in pre-
17 paring for and responding to the escalating burden of epi-
18 lepsy. Such assessment shall include—

19 “(1) recommendations for priority actions;

20 “(2) a description of the steps that have been,
21 or should be, taken to implement such recommenda-
22 tions; and

23 “(3) such other items as the Secretary deter-
24 mines appropriate.

25 “(c) ADVISORY COUNCIL.—

1 “(1) IN GENERAL.—The Secretary shall estab-
 2 lish and maintain an Advisory Council on Epilepsy
 3 Research, Care, and Services (referred to in this sec-
 4 tion as the ‘Advisory Council’) to advise the Sec-
 5 retary on epilepsy-related issues.

6 “(2) MEMBERSHIP.—The Advisory Council
 7 shall be comprised of—

8 “(A) representatives appointed by the Sec-
 9 retary from relevant Federal departments and
 10 agencies, including—

11 “(i) the National Institutes of Health;

12 “(ii) the Centers for Medicare & Med-
 13 icaid Services;

14 “(iii) the Centers for Disease Control
 15 and Prevention;

16 “(iv) the Food and Drug Administra-
 17 tion;

18 “(v) the Health Resources and Serv-
 19 ices Administration;

20 “(vi) the Department of Defense; and

21 “(vii) the Department of Veterans Af-
 22 fairs; and

23 “(B) expert non-Federal members ap-
 24 pointed by the Secretary that reflect the diver-
 25 sity of epilepsy, including—

1 “(i) 4 individuals, each of whom is liv-
2 ing with a different type of epilepsy;

3 “(ii) 2 family caregivers for individ-
4 uals with epilepsy;

5 “(iii) 2 licensed or accredited health
6 care providers supported by a relevant pro-
7 fessional medical society, including at least
8 1 epileptologist or neurologist;

9 “(iv) 2 biomedical researchers with
10 epilepsy-related expertise in basic,
11 translational, or clinical population science
12 or drug development science; and

13 “(v) 3 representatives from 3 separate
14 nonprofit organizations directly connected
15 with epilepsy that have demonstrated expe-
16 rience in epilepsy research or epilepsy pa-
17 tient care and other services.

18 ~~“(3) MEETINGS.—~~

19 ~~“(A) IN GENERAL.—~~The Advisory Council
20 shall meet at least once each quarter.

21 ~~“(B) MEETINGS WITH OTHER EXPERTS.—~~

22 Not later than 2 years after the date of enact-
23 ment of the National Plan for Epilepsy Act,
24 and every 2 years thereafter, the Advisory
25 Council shall convene a meeting of Federal and

1 non-Federal organizations to discuss epilepsy
2 research.

3 “(C) PUBLIC MEETINGS.—All meetings of
4 the Advisory Council shall be open to the pub-
5 lic.

6 “(4) REPORTING.—Not later than 18 months
7 after the date of enactment of the National Plan for
8 Epilepsy Act, and every 2 years thereafter, the Advi-
9 sory Council shall provide to the Secretary and Con-
10 gress a report containing—

11 “(A) an evaluation of all federally funded
12 efforts in preventing, diagnosing, treating, and
13 curing epilepsy, and the outcomes of such ef-
14 forts;

15 “(B) recommendations for priority actions
16 to better coordinate, expand, and better support
17 Federal programs in order to better support
18 people with epilepsy, epilepsy research, and
19 data collection;

20 “(C) recommendations to—

21 “(i) provide effective, timely, and re-
22 sponsive diagnosis treatment and care to
23 improve health outcomes and quality of
24 life;

1 “(ii) foster research and innovation
2 leading to more effective treatments and
3 potential cures for epilepsy;

4 “(iii) strengthen data and information
5 systems including better surveillance of
6 epilepsy;

7 “(iv) increase public awareness about
8 epilepsy and reduce stigma and discrimina-
9 tion;

10 “(v) increase access to expert and spe-
11 cialized care for people with epilepsy;

12 “(vi) eliminate access to care dispari-
13 ties experienced by individuals with epi-
14 lepsy;

15 “(vii) prevent sudden unexpected
16 death in epilepsy and other epilepsy-related
17 mortalities;

18 “(viii) reduce the financial impact of
19 epilepsy on families living with epilepsy;

20 “(ix) prevent epilepsy and promote
21 healthy behaviors; and

22 “(x) an evaluation of the implementa-
23 tion of the National Plan, and its out-
24 comes.

1 “(d) ANNUAL REPORTS.—The Secretary shall annu-
2 ally submit to Congress a report that includes—

3 “(1) an evaluation of all federally funded efforts
4 in epilepsy research, prevention, diagnosis, treat-
5 ment, clinical care, and institutional, home, and
6 community-based programs, and the outcomes of
7 such efforts;

8 “(2) recommendations for—

9 “(A) priority actions based on the most re-
10 cent assessment submitted by the Secretary
11 under subsection (b) and the recommendations
12 contained in the most recent report of the Advi-
13 sory Council under subsection (c)(4);

14 “(B) priority actions to improve all feder-
15 ally funded efforts in epilepsy research, preven-
16 tion, diagnosis, treatment, clinical care, and in-
17 stitutional, home, and community-based pro-
18 grams; and

19 “(C) implementation steps to address pri-
20 ority actions described in subparagraphs (A)
21 and (B); and

22 “(3) a description of the progress made in ear-
23 rying out the National Plan.

24 “(e) DATA SHARING.—Agencies both within the De-
25 partment of Health and Human Services and outside of

1 such Department that have data relating to epilepsy shall
 2 share such data with the Secretary as necessary to enable
 3 the Secretary to complete the reports described in sub-
 4 section (d).

5 “(f) SUNSET.—This section shall cease to be effective
 6 on December 31, 2035.”

7 **SECTION 1. SHORT TITLE.**

8 *This Act may be cited as the “National Plan for Epi-*
 9 *lepsy Act”.*

10 **SEC. 2. REVIEW TO IMPROVE EPILEPSY PROGRAMS, RE-**
 11 **SEARCH, PREVENTION, AND CARE.**

12 (a) *IN GENERAL.*—The Secretary of Health and
 13 Human Services (referred to in this section as the “Sec-
 14 retary”) shall review and, as necessary and appropriate,
 15 provide recommendations to Congress regarding, and up-
 16 date existing Federal programs, activities, and strategic
 17 plans related to, epilepsy research, prevention, early identi-
 18 fication, diagnosis, and treatment for purposes of identi-
 19 fying and addressing knowledge gaps and improving health
 20 outcomes related to epilepsy.

21 (b) *CONTENT.*—The review under subsection (a) shall
 22 include—

23 (1) *a review of findings from evidence-based re-*
 24 *search on epilepsy, the status of ongoing, federally-*
 25 *funded research on epilepsy, knowledge gaps related to*

1 *epilepsy, and disparities in populations with epi-*
2 *lepsy;*

3 *(2) a review of Federal programs related to epi-*
4 *lepsy research, prevention, early identification, diag-*
5 *nosis, and treatment, which shall include consider-*
6 *ation of—*

7 *(A) gaps in, and opportunities for, coordi-*
8 *nation among such programs;*

9 *(B) opportunities to inform global efforts to*
10 *prevent, diagnose, treat, and cure epilepsy, as*
11 *appropriate;*

12 *(C) near- and long-term goals of such pro-*
13 *grams to improve research, prevention, early*
14 *identification, diagnosis, and treatment of epi-*
15 *lepsy; and*

16 *(D) the level of Federal investment in pre-*
17 *venting, diagnosing, treating, and curing epi-*
18 *lepsy;*

19 *(3) consideration of opportunities to—*

20 *(A) improve collaboration between Federal*
21 *agencies and relevant stakeholders to address*
22 *gaps in programs, research, and services;*

23 *(B) eliminate knowledge gaps in research on*
24 *epilepsy, including a review of the impact of epi-*

1 *lepsy on the health and well-being of individuals*
 2 *with epilepsy and their caregivers;*

3 *(C) improve early diagnosis and coordina-*
 4 *tion of the care and treatment of individuals*
 5 *with epilepsy;*

6 *(D) better prevent sudden unexpected death*
 7 *in epilepsy and other epilepsy-related mortali-*
 8 *ties;*

9 *(E) improve surveillance of epilepsy; and*

10 *(F) support the development of new treat-*
 11 *ments, strategies, and other approaches to pre-*
 12 *vent, diagnose, treat, and cure epilepsy or to en-*
 13 *hance functioning and improve quality of life for*
 14 *individuals with epilepsy and their caregivers;*
 15 *and*

16 *(4) a review of current public health strategies,*
 17 *and consideration of additional evidence-based strate-*
 18 *gies, related to epilepsy.*

19 *(c) EXTERNAL INPUT.—To inform the review under*
 20 *subsection (a), the Secretary shall regularly convene and*
 21 *solicit input from other Federal agencies, as appropriate,*
 22 *and relevant stakeholders, including patient advocates and*
 23 *non-Federal subject matter experts.*

24 *(d) REPORT.—Not later than 2 years after the date*
 25 *of the enactment of this Act, the Secretary shall submit to*

1 *the Committee on Health, Education, Labor, and Pensions*
2 *of the Senate and the Committee on Energy and Commerce*
3 *of the House of Representatives a report on the findings*
4 *of the review conducted under subsection (a), including—*

5 *(1) a description of steps the Secretary took to*
6 *solicit stakeholder input pursuant to subsection (c)*
7 *and a summary of feedback received from, and needs*
8 *identified by, such stakeholders;*

9 *(2) recommendations to improve coordination*
10 *and support of Federal programs in order to better*
11 *support people with epilepsy, epilepsy research, and*
12 *data collection, and proposals for implementation of*
13 *such recommendations, as appropriate; and*

14 *(3) any changes to Federal programs, activities,*
15 *or strategic plans recommended by the Secretary*
16 *based on the review, and any statutory or other bar-*
17 *riers that impede implementation of such changes.*

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