

118TH CONGRESS
2D SESSION

S. 5353

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

IN THE SENATE OF THE UNITED STATES

NOVEMBER 20, 2024

Mr. SCHMITT (for himself and Ms. KLOBUCHAR) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “National Plan for Epi-
5 lepsy Act”.

6 **SEC. 2. FINDINGS.**

7 Congress finds as follows:

8 (1) Epilepsy is a brain disorder that causes re-
9 curring and unprovoked seizures and affects people

1 of all ages, affecting nearly 3,000,000 adults and
2 456,000 children in the United States.

3 (2) Epilepsy and seizures can develop in any
4 person at any age. One in 26 people will develop a
5 form of epilepsy in their lifetime, with people from
6 all demographic groups and walks of life being im-
7 pacted.

8 (3) In approximately half of all cases of epi-
9 lepsy, the underlying cause of the disease is un-
10 known.

11 (4) Epilepsy is a spectrum disease comprised of
12 many diagnoses and an ever-growing number of rare
13 epilepsies. There are many different types of sei-
14 zures and varying levels of seizure control.

15 (5) Over 30 percent of people with epilepsy live
16 with uncontrolled seizures.

17 (6) Individuals with epilepsy have a 3-times
18 higher risk of early death than the general popu-
19 lation and that risk is even higher for individuals
20 with uncontrolled seizures.

21 (7) Thirty-two percent of adults with epilepsy
22 are unable to work.

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

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

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

5 Part B of title III of the Public Health Service Act
6 (42 U.S.C. 243 et seq.) is amended by adding at the end
7 the following:

8 **“SEC. 320C. PROGRAMS RELATING TO EPILEPSY.**

9 “(a) NATIONAL PLAN FOR EPILEPSY.—

10 “(1) IN GENERAL.—The Secretary shall carry
11 out a national project, to be known as the ‘National
12 Plan for Epilepsy’ (referred to in this section as the
13 ‘National Plan’), to prevent, diagnose, treat, and
14 cure epilepsy.

15 “(2) ACTIVITIES.—In carrying out the National
16 Plan, the Secretary shall—

17 “(A) establish, maintain, and periodically
18 update an integrated national plan to prevent,
19 diagnose, treat, and cure epilepsy;

20 “(B) provide information, including an es-
21 timate of the level of Federal investment in pre-
22 venting, diagnosing, treating, and curing epi-
23 lepsy;

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

1 “(D) encourage the development of safe
2 and effective treatments, strategies, and other
3 approaches to prevent, diagnose, treat, and cure
4 epilepsy or to enhance functioning and improve
5 quality of life for individuals with epilepsy and
6 their caregivers;

7 “(E) improve the—

8 “(i) early diagnosis of epilepsy; and

9 “(ii) coordination of the care and
10 treatment of individuals living with epi-
11 lepsy;

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

15 “(G) solicit public comments and consider
16 consensus recommendations from collaborations
17 in the epilepsy community;

18 “(H) carry out an annual assessment on
19 progress of the activities described in this sub-
20 section;

21 “(I) coordinate with international bodies,
22 to the degree possible, to integrate and inform
23 the global mission to prevent, diagnose, treat,
24 and cure epilepsy; and

1 “(J) carry out other such activities as the
2 Secretary determines appropriate.

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

9 “(1) recommendations for priority actions;

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

13 “(3) such other items as the Secretary deter-
14 mines appropriate.

15 “(c) ADVISORY COUNCIL.—

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

21 “(2) MEMBERSHIP.—The Advisory Council
22 shall be comprised of—

23 “(A) representatives appointed by the Sec-
24 retary from relevant Federal departments and
25 agencies, including—

1 “(i) the National Institutes of Health;

2 “(ii) the Centers for Medicare & Med-
3 icaid Services;

4 “(iii) the Centers for Disease Control
5 and Prevention;

6 “(iv) the Food and Drug Administra-
7 tion;

8 “(v) the Health Resources and Serv-
9 ices Administration;

10 “(vi) the Department of Defense; and

11 “(vii) the Department of Veterans Af-
12 fairs; and

13 “(B) expert non-Federal members ap-
14 pointed by the Secretary that reflect the diver-
15 sity of epilepsy, including—

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

18 “(ii) 2 family caregivers for individ-
19 uals with epilepsy;

20 “(iii) 2 licensed or accredited health
21 care providers supported by a relevant pro-
22 fessional medical society, including at least
23 1 epileptologist or neurologist;

24 “(iv) 2 biomedical researchers with
25 epilepsy-related expertise in basic,

1 translational, or clinical population science
2 or drug development science; and

3 “(v) 3 representatives from 3 separate
4 nonprofit organizations directly connected
5 with epilepsy that have demonstrated expe-
6 rience in epilepsy research or epilepsy pa-
7 tient care and other services.

8 “(3) MEETINGS.—

9 “(A) IN GENERAL.—The Advisory Council
10 shall meet at least once each quarter.

11 “(B) MEETINGS WITH OTHER EXPERTS.—
12 Not later than 2 years after the date of enact-
13 ment of the National Plan for Epilepsy Act,
14 and every 2 years thereafter, the Advisory
15 Council shall convene a meeting of Federal and
16 non-Federal organizations to discuss epilepsy
17 research.

18 “(C) PUBLIC MEETINGS.—All meetings of
19 the Advisory Council shall be open to the pub-
20 lic.

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

1 “(A) an evaluation of all federally funded
2 efforts in preventing, diagnosing, treating, and
3 curing epilepsy, and the outcomes of such ef-
4 forts;

5 “(B) recommendations for priority actions
6 to better coordinate, expand, and better support
7 Federal programs in order to better support
8 people with epilepsy, epilepsy research, and
9 data collection;

10 “(C) recommendations to—

11 “(i) provide effective, timely, and re-
12 sponsive diagnosis treatment and care to
13 improve health outcomes and quality of
14 life;

15 “(ii) foster research and innovation
16 leading to more effective treatments and
17 potential cures for epilepsy;

18 “(iii) strengthen data and information
19 systems including better surveillance of
20 epilepsy;

21 “(iv) increase public awareness about
22 epilepsy and reduce stigma and discrimina-
23 tion;

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

1 “(vi) eliminate access to care dispari-
2 ties experienced by individuals with epi-
3 lepsy;

4 “(vii) prevent sudden unexpected
5 death in epilepsy and other epilepsy-related
6 mortalities;

7 “(viii) reduce the financial impact of
8 epilepsy on families living with epilepsy;

9 “(ix) prevent epilepsy and promote
10 healthy behaviors; and

11 “(x) an evaluation of the implementa-
12 tion of the National Plan, and its out-
13 comes.

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

16 “(1) an evaluation of all federally-funded efforts
17 in epilepsy research, prevention, diagnosis, treat-
18 ment, clinical care, and institutional-, home-, and
19 community-based programs, and the outcomes of
20 such efforts;

21 “(2) recommendations for—

22 “(A) priority actions based on the most re-
23 cent assessment submitted by the Secretary
24 under subsection (b) and the recommendations

1 contained in the most recent report of the Advi-
2 sory Council under subsection (c)(4);

3 “(B) priority actions to improve all feder-
4 ally-funded efforts in epilepsy research, preven-
5 tion, diagnosis, treatment, clinical care, and in-
6 stitutional-, home-, and community-based pro-
7 grams; and

8 “(C) implementation steps to address pri-
9 ority actions described in subparagraphs (A)
10 and (B); and

11 “(3) a description of the progress made in car-
12 rying out the National Plan.

13 “(e) DATA SHARING.—Agencies both within the De-
14 partment of Health and Human Services and outside of
15 such Department that have data relating to epilepsy shall
16 share such data with the Secretary as necessary to enable
17 the Secretary to complete the reports described in sub-
18 section (d).

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

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