

118TH CONGRESS  
2D SESSION

**S.** \_\_\_\_\_

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

---

IN THE SENATE OF THE UNITED STATES

---

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

---

## **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  
2 470,000 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; and

21           “(I) carry out other such activities as the  
22           Secretary determines appropriate.

23           “(b) ANNUAL ASSESSMENT.—Not later than 2 years  
24           after the date of enactment of the National Plan for Epi-  
25           lepsy Act, and annually thereafter, the Secretary shall

1 carry out an assessment of the Nation’s progress in pre-  
2 paring for and responding to the escalating burden of epi-  
3 lepsy. Such assessment shall include—

4 “(1) recommendations for priority actions;

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

8 “(3) such other items as the Secretary deter-  
9 mines appropriate.

10 “(c) ADVISORY COUNCIL.—

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

16 “(2) MEMBERSHIP.—The Advisory Council  
17 shall be comprised of—

18 “(A) representatives appointed by the Sec-  
19 retary from relevant Federal departments and  
20 agencies, including—

21 “(i) the National Institutes of Health;

22 “(ii) the Centers for Medicare & Med-  
23 icaid Services;

24 “(iii) the Centers for Disease Control  
25 and Prevention;

1 “(iv) the Food and Drug Administra-  
2 tion;

3 “(v) the Health Resources and Serv-  
4 ices Administration;

5 “(vi) the Department of Defense; and

6 “(vii) the Department of Veterans Af-  
7 fairs; and

8 “(B) expert non-Federal members ap-  
9 pointed by the Secretary that reflect the diver-  
10 sity of epilepsy, including—

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

13 “(ii) 2 family caregivers for individ-  
14 uals with epilepsy;

15 “(iii) 2 licensed or accredited health  
16 care providers supported by a relevant pro-  
17 fessional medical society, including at least  
18 1 epileptologist or neurologist;

19 “(iv) 2 biomedical researchers with  
20 epilepsy-related expertise in basic,  
21 translational, or clinical population science  
22 or drug development science; and

23 “(v) 3 representatives from 3 separate  
24 nonprofit organizations directly connected  
25 with epilepsy that have demonstrated expe-

1                    rience in epilepsy research or epilepsy pa-  
2                    tient care and other services.

3                    “(3) MEETINGS.—

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

6                    “(B) MEETINGS WITH OTHER EXPERTS.—

7                    Not later than 2 years after the date of enact-  
8                    ment of the National Plan for Epilepsy Act,  
9                    and every 2 years thereafter, the Advisory  
10                    Council shall convene a meeting of Federal and  
11                    non-Federal organizations to discuss epilepsy  
12                    research.

13                    “(C) PUBLIC MEETINGS.—All meetings of  
14                    the Advisory Council shall be open to the pub-  
15                    lic.

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

21                    “(A) an evaluation of all federally funded  
22                    efforts in preventing, diagnosing, treating, and  
23                    curing epilepsy, and the outcomes of such ef-  
24                    forts;

1           “(B) recommendations for priority actions  
2           to better coordinate, expand, and better support  
3           Federal programs in order to better support  
4           people with epilepsy, epilepsy research, and  
5           data collection;

6           “(C) recommendations to—

7                   “(i) provide effective, timely, and re-  
8                   sponsive diagnosis treatment and care to  
9                   improve health outcomes and quality of  
10                  life;

11                   “(ii) foster research and innovation  
12                   leading to more effective treatments and  
13                   potential cures for epilepsy;

14                   “(iii) strengthen data and information  
15                   systems including better surveillance of  
16                   epilepsy;

17                   “(iv) increase public awareness about  
18                   epilepsy and reduce stigma and discrimina-  
19                   tion;

20                   “(v) eliminate access to care dispari-  
21                   ties experienced by individuals with epi-  
22                   lepsy;

23                   “(vi) prevent sudden unexpected death  
24                   in epilepsy and other epilepsy-related mor-  
25                   talities;



1                   “(vii) reduce the financial impact of  
2                   epilepsy on families living with epilepsy;

3                   “(viii) prevent epilepsy and promote  
4                   healthy behaviors; and

5                   “(ix) an evaluation of the implementa-  
6                   tion of the National Plan, and its out-  
7                   comes.

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

10                   “(1) an evaluation of all federally-funded efforts  
11                   in epilepsy research, prevention, diagnosis, treat-  
12                   ment, clinical care, and institutional-, home-, and  
13                   community-based programs, and the outcomes of  
14                   such efforts;

15                   “(2) recommendations for—

16                           “(A) priority actions based on the most re-  
17                           cent assessment submitted by the Secretary  
18                           under subsection (b) and the recommendations  
19                           contained in the most recent report of the Advi-  
20                           sory Council under subsection (c)(4);

21                           “(B) priority actions to improve all feder-  
22                           ally-funded efforts in epilepsy research, preven-  
23                           tion, diagnosis, treatment, clinical care, and in-  
24                           stitutional-, home-, and community-based pro-  
25                           grams; and

1                   “(C) implementation steps to address pri-  
2                   ority actions described in subparagraphs (A)  
3                   and (B); and

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

6                   “(e) DATA SHARING.—Agencies both within the De-  
7                   partment of Health and Human Services and outside of  
8                   such Department that have data relating to epilepsy shall  
9                   share such data with the Secretary as necessary to enable  
10                  the Secretary to complete the reports described in sub-  
11                  section (d).

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