



AMENDMENT NO. _____ Calendar No. _____

Purpose: In the nature of a substitute.

IN THE SENATE OF THE UNITED STATES—119th Cong., 2d Sess.

S. 494

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

Referred to the Committee on _____ and
ordered to be printed

Ordered to lie on the table and to be printed

AMENDMENT IN THE NATURE OF A SUBSTITUTE intended
to be proposed by _____

Viz:

1 Strike all after the enacting clause and insert the fol-
2 lowing:

3 **SECTION 1. SHORT TITLE.**

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

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

8 (a) IN GENERAL.—The Secretary of Health and
9 Human Services (referred to in this section as the “Sec-
10 retary”) shall review and, as necessary and appropriate,
11 provide recommendations to Congress regarding, and up-
12 date existing Federal programs, activities, and strategic

1 plans related to, epilepsy research, prevention, early iden-
2 tification, diagnosis, and treatment for purposes of identi-
3 fying and addressing knowledge gaps and improving
4 health outcomes related to epilepsy.

5 (b) CONTENT.—The review under subsection (a) shall
6 include—

7 (1) a review of findings from evidence-based re-
8 search on epilepsy, the status of ongoing, federally-
9 funded research on epilepsy, knowledge gaps related
10 to epilepsy, and disparities in populations with epi-
11 lepsy;

12 (2) a review of Federal programs related to epi-
13 lepsy research, prevention, early identification, diag-
14 nosis, and treatment, which shall include consider-
15 ation of—

16 (A) gaps in, and opportunities for, coordi-
17 nation among such programs;

18 (B) opportunities to inform global efforts
19 to prevent, diagnose, treat, and cure epilepsy,
20 as appropriate;

21 (C) near- and long-term goals of such pro-
22 grams to improve research, prevention, early
23 identification, diagnosis, and treatment of epi-
24 lepsy; and

1 (D) the level of Federal investment in pre-
2 venting, diagnosing, treating, and curing epi-
3 lepsy;

4 (3) consideration of opportunities to—

5 (A) improve collaboration between Federal
6 agencies and relevant stakeholders to address
7 gaps in programs, research, and services;

8 (B) eliminate knowledge gaps in research
9 on epilepsy, including a review of the impact of
10 epilepsy on the health and well-being of individ-
11 uals with epilepsy and their caregivers;

12 (C) improve early diagnosis and coordina-
13 tion of the care and treatment of individuals
14 with epilepsy;

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

18 (E) improve surveillance of epilepsy; and

19 (F) support the development of new treat-
20 ments, strategies, and other approaches to pre-
21 vent, diagnose, treat, and cure epilepsy or to
22 enhance functioning and improve quality of life
23 for individuals with epilepsy and their care-
24 givers; and

1 (4) a review of current public health strategies,
2 and consideration of additional evidence-based strat-
3 egies, related to epilepsy.

4 (c) EXTERNAL INPUT.—To inform the review under
5 subsection (a), the Secretary shall regularly convene and
6 solicit input from other Federal agencies, as appropriate,
7 and relevant stakeholders, including patient advocates and
8 non-Federal subject matter experts.

9 (d) REPORT.—Not later than 2 years after the date
10 of the enactment of this Act, the Secretary shall submit
11 to the Committee on Health, Education, Labor, and Pen-
12 sions of the Senate and the Committee on Energy and
13 Commerce of the House of Representatives a report on
14 the findings of the review conducted under subsection (a),
15 including—

16 (1) a description of steps the Secretary took to
17 solicit stakeholder input pursuant to subsection (c)
18 and a summary of feedback received from, and
19 needs identified by, such stakeholders;

20 (2) recommendations to improve coordination
21 and support of Federal programs in order to better
22 support people with epilepsy, epilepsy research, and
23 data collection, and proposals for implementation of
24 such recommendations, as appropriate; and

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