

119<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

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

To amend the Public Health Service Act to require the Director of the National Institutes of Health to develop a national strategy to address young adult cancers, and for other purposes.

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IN THE SENATE OF THE UNITED STATES

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Mr. MARKEY introduced the following bill; which was read twice and referred to the Committee on \_\_\_\_\_

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**A BILL**

To amend the Public Health Service Act to require the Director of the National Institutes of Health to develop a national strategy to address young adult cancers, 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 “Asal Sayas National  
5        Strategy on Young Adult Cancers Act”.

6        **SEC. 2. FINDINGS.**

7        Congress finds that—

1           (1) cancer is the second most common cause of  
2 death in the United States, with over 2,000,000 new  
3 cases diagnosed annually and an expected 626,140  
4 cancer deaths in 2026;

5           (2) the incidence of cancer in individuals ages  
6 18 to 49 (referred to in this section as “young  
7 adults”), has risen 79 percent globally between 1990  
8 and 2019, and mortality from cancer in that age  
9 group has risen by 28 percent;

10          (3) the incidence of young adult cancers is pre-  
11 dicted to increase by 30 percent globally from 2019  
12 to 2030;

13          (4) each year in the United States, approxi-  
14 mately 200,000 young adults are diagnosed with  
15 cancer and approximately 30,000 young adults die  
16 from cancer;

17          (5) the incidence of cancers in young adult  
18 women is now 82 percent higher than the incidence  
19 of cancers in young adult men, and cancers in young  
20 adult women has increased by 51 percent since  
21 2002;

22          (6) the economic cost in the United States of  
23 young adult cancers is estimated at  
24 \$50,000,000,000 to \$80,000,000,000 annually, due  
25 to costs relating to medical care, out-of-pocket ex-

1       penses, lost productivity, caregiver burden, and pre-  
2       mature deaths;

3           (7) rates of young adult cancers are increasing  
4       significantly for digestive cancers, including  
5       colorectal and pancreatic cancers, lung cancers, gyn-  
6       ecological cancers, including cervical, uterine, and  
7       ovarian cancers, breast cancers, prostate cancers,  
8       testicular cancers, thyroid cancers, melanoma, sar-  
9       coma, lymphoma, leukemia, and head and neck can-  
10      cers;

11          (8) colorectal cancers are the leading cause of  
12      young adult cancer-related deaths in the United  
13      States, and the second-leading cause of cancer over-  
14      all;

15          (9) lung cancer is the leading cause of cancer  
16      death in both men and women in the United States,  
17      and rates are rising among young adults, including  
18      for non-smokers, the majority of whom are women;

19          (10) some cancers, including colorectal cancers  
20      and lung cancers, are more likely to be more ad-  
21      vanced at diagnosis and have worse survival rates  
22      for young adults than for individuals in other age  
23      groups;

24          (11) current eligibility criteria for cancer  
25      screening, including for colorectal and lung cancers,

1 fail to identify many young adults who develop these  
2 diseases;

3 (12) young adult cancers have significant short-  
4 and long-term social and economic impacts on indi-  
5 viduals, their families, and society, and are linked to  
6 higher risk of long-term health problems in sur-  
7 vivors;

8 (13) the risk factors contributing to young  
9 adult cancers remain complex and may include inter-  
10 action of genetic and biological factors, as well as  
11 lifestyle and environmental exposures, making identi-  
12 fication of at-risk groups difficult;

13 (14) young adults with cancer face an average  
14 delay of 7 months between symptom onset and treat-  
15 ment, versus 1 month for individuals age 50 and  
16 over; and

17 (15) barriers to diagnosis for young adult can-  
18 cers include screening ineligibility linked to age,  
19 delay in presentation to primary care after symptom  
20 appearance, more frequent misattribution of symp-  
21 toms to less severe conditions, and delay in referral  
22 to a cancer specialist.

1 **SEC. 3. NATIONAL STRATEGY TO ADDRESS YOUNG ADULT**  
2 **CANCERS.**

3 Section 402 of the Public Health Service Act (42  
4 U.S.C. 282) is amended by adding the following:

5 “(p) ASAL SAYAS NATIONAL STRATEGY ON YOUNG  
6 ADULT CANCERS.—

7 “(1) IN GENERAL.—Not later than 18 months  
8 after the date of enactment of the Asal Sayas Na-  
9 tional Strategy on Young Adult Cancers Act, the Di-  
10 rector of NIH shall develop and submit to the rel-  
11 evant committees of Congress, and post on the  
12 websites of the National Institutes of Health and the  
13 clearinghouse established pursuant to paragraph  
14 (2)(G), a national strategy to address young adult  
15 cancers, to be known as the ‘Asal Sayas National  
16 Strategy on Young Adult Cancers’.

17 “(2) REQUIREMENTS.—The national strategy  
18 under paragraph (1) shall—

19 “(A) conduct and provide an inventory of  
20 current young adult cancer research programs,  
21 initiatives, and services across the National In-  
22 stitutes of Health and other Federal agencies;

23 “(B) develop a national education cam-  
24 paign for the public and health care profes-  
25 sionals on the symptoms of, and risk factors  
26 for, young adult cancers, which shall—

1                   “(i) identify culturally relevant stra-  
2                   tegic priorities and objectives for such na-  
3                   tional education campaign;

4                   “(ii) provide education to, and raise  
5                   public awareness among, the general public  
6                   about symptoms and risk factors for young  
7                   adult cancers; and

8                   “(iii) provide education to primary  
9                   care, emergency, obstetrics and gynecology,  
10                  pulmonary, and gastrointestinal health  
11                  care professionals and other health care  
12                  professionals regarding the signs, symp-  
13                  toms, and risk factors for the leading types  
14                  of young adult cancers in the United  
15                  States;

16                  “(C) identify strategic research priorities  
17                  and objectives across biomedical, behavioral,  
18                  and environmental research areas, including  
19                  by—

20                         “(i) conducting an assessment of  
21                         young adult cancer research, including  
22                         areas of opportunity with respect to basic,  
23                         clinical, epidemiologic, and translational re-  
24                         search;



1           “(ii) differences among young adult  
2 cancers in total and by cancer type among  
3 sociodemographic groups, including by—

4                   “(I) sex;

5                   “(II) race and ethnicity;

6                   “(III) status as a veteran, mem-  
7 ber of the Armed Forces, or family  
8 member of a veteran or member of  
9 the Armed Forces;

10                  “(IV) disability status;

11                  “(V) professions that may in-  
12 crease cancer risk; and

13                  “(VI) Tribal populations, rural  
14 populations, and medically under-  
15 served populations (as defined in sec-  
16 tion 330(b)(3));

17           “(iii) multi-institute and multi-agency  
18 priorities, including coordination of re-  
19 search among the national research insti-  
20 tutes, the national centers, and Federal  
21 agencies;

22           “(iv) barriers to participation in clin-  
23 ical trials for young adults;

24           “(v) special needs associated with  
25 treatment among the non-pediatric young

1 adult population, such as concerns associ-  
2 ated with preserving fertility, mental  
3 health issues, and employment;

4 “(vi) existing Federal resources, such  
5 as reports, databases, and guidance; and

6 “(vii) other factors the Director of  
7 NIH determines appropriate, in consulta-  
8 tion with the Director of the National Can-  
9 cer Institute, the heads of other national  
10 research institutes, and the heads of Fed-  
11 eral agencies;

12 “(E) provide recommendations with re-  
13 spect to—

14 “(i) advancing biomedical, lifestyle,  
15 and environmental research into the causes  
16 of young adult cancers, by type of cancer;

17 “(ii) improving methods for early de-  
18 tection and screening of young adult can-  
19 cers, by type of cancer, including education  
20 campaigns for the public and health care  
21 professionals and resources to increase  
22 awareness of symptoms;

23 “(iii) improving screening guidance  
24 and the development of new diagnostics

1 with respect to various types of young  
2 adult cancers;

3 “(iv) reducing barriers to insurance  
4 coverage of screening for young adult can-  
5 cers;

6 “(v) ensuring timely reviews of cancer  
7 screening recommendations by the United  
8 States Preventive Services Task Force that  
9 assess research findings for cancers that  
10 are rising in young adults;

11 “(vi) applying technologies, including  
12 innovative electronic health record tools, to  
13 identify biomarkers and other risk factors  
14 and to target treatment options for young  
15 adult cancers;

16 “(vii) applying technologies, including  
17 innovative electronic health record tools, to  
18 increase the use by health care providers of  
19 recommendations for identification of  
20 symptoms, family history, hereditary syn-  
21 dromes, or other risk factors that could  
22 contribute to the young adult cancer diag-  
23 nosis;

24 “(viii) evaluating current therapies  
25 and developing new treatments, including

1 biomarker identification and precision  
2 medicine, for young adult cancers;

3 “(ix) addressing and disseminating  
4 prevention strategies;

5 “(x) addressing barriers to conducting  
6 research regarding young adult cancers;

7 “(xi) addressing barriers to participa-  
8 tion in clinical trials for young adults with  
9 cancer;

10 “(xii) increasing efforts to improve  
11 medical education and knowledge among  
12 health care professionals of young adult  
13 cancers, including risk factors, symptoms,  
14 screening and early detection techniques,  
15 prevention, and treatment options;

16 “(xiii) establishing within the Na-  
17 tional Cancer Institute a National Centers  
18 of Excellence for Young Adult Cancers  
19 program (or a comparable alternative) that  
20 would create and support hubs across the  
21 United States for research, clinical care,  
22 and public and professional education;

23 “(xiv) supporting the psychosocial  
24 needs of individuals undergoing treatment  
25 for young adult cancers, including family,

1 fertility preservation, and work-related  
2 issues;

3 “(xv) addressing the needs of care-  
4 givers of young adult cancer patients; and

5 “(xvi) other topics, as determined by  
6 the Director of NIH, in consultation with  
7 the Federal Coordinating Committee on  
8 Young Adult Cancers established under  
9 paragraph (3)(A);

10 “(F) describe opportunities for collabora-  
11 tion with Federal departments and agencies  
12 and the private sector, as appropriate; and

13 “(G) establish an online Federal clearing-  
14 house to provide to the general public, patients,  
15 caregivers, health care professionals, and re-  
16 searchers information on young adult cancers,  
17 with resources, including—

18 “(i) information on risk factors, symp-  
19 toms, and screening eligibility;

20 “(ii) information regarding research  
21 findings, clinical trials, and research fund-  
22 ing opportunities; and

23 “(iii) clinical practice guidelines for  
24 health care professionals.



1 Heart, Lung, and Blood Institute, the Na-  
2 tional Institute of Diabetes and Digestive  
3 and Kidney Diseases, the Eunice Kennedy  
4 Shriver National Institute of Child Health  
5 and Human Development, the National  
6 Human Genome Research Institute, the  
7 National Institute of Mental Health, the  
8 Office of Research on Women’s Health,  
9 and the National Institute on Minority  
10 Health and Health Disparities;

11 “(iii) the Director of the Office of  
12 Science and Technology Policy;

13 “(iv) the Secretary of Health and  
14 Human Services;

15 “(v) the Director of the Centers for  
16 Disease Control and Prevention;

17 “(vi) the Administrator of the Centers  
18 for Medicare & Medicaid Services;

19 “(vii) the Commissioner of Food and  
20 Drugs;

21 “(viii) the Assistant Secretary for  
22 Mental Health and Substance Use;

23 “(ix) the Director of the Indian  
24 Health Service;

1                   “(x) the Director of the Office of Mi-  
2                   nority Health of the Department of Health  
3                   and Human Services;

4                   “(xi) the Director of the Office on  
5                   Women’s Health of the Department of  
6                   Health and Human Services;

7                   “(xii) the Director of the Agency for  
8                   Healthcare Research and Quality;

9                   “(xiii) the Director of the Advanced  
10                  Research Projects Agency–Health;

11                  “(xiv) the Assistant Secretary of De-  
12                  fense for Health Affairs;

13                  “(xv) the Under Secretary for Health  
14                  for the Department of Veterans Affairs;

15                  “(xvi) the Director of the Office of  
16                  Science of the Department of Energy;

17                  “(xvii) the Director of the National  
18                  Science Foundation;

19                  “(xviii) the Administrator of the Envi-  
20                  ronmental Protection Agency;

21                  “(xix) representatives of patient advo-  
22                  cacy groups;

23                  “(xx) representatives of academic re-  
24                  search institutions;

1                   “(xxi) representatives of the bio-  
2                   medical industry;

3                   “(xxii) representatives and leaders of  
4                   community health institutions; and

5                   “(xxiii) others, as determined by the  
6                   Director.

7                   “(4) DEFINITIONS.—In this subsection:

8                   “(A) RELEVANT COMMITTEES OF CON-  
9                   GRESS.—The term ‘relevant committees of Con-  
10                  gress’ means—

11                  “(i) the Committee on Health, Edu-  
12                  cation, Labor, and Pensions of the Senate;

13                  “(ii) the Committee on Finance of the  
14                  Senate;

15                  “(iii) the Committee on Appropria-  
16                  tions of the Senate;

17                  “(iv) the Committee on Energy and  
18                  Commerce of the House of Representa-  
19                  tives;

20                  “(v) the Committee on Ways and  
21                  Means of the House of Representatives;  
22                  and

23                  “(vi) the Committee on Appropria-  
24                  tions of the House of Representatives.

1                   “(B) YOUNG ADULT.—The term ‘young  
2                   adult’ means an individual between the ages of  
3                   18 and 49.”.