

107TH CONGRESS
2D SESSION

H. R. 5139

To amend title XVIII of the Social Security Act to provide certain caregivers with access to Medicare benefits, to amend the Internal Revenue Code of 1986 to provide a long-term care tax credit, and to provide for programs within the Department of Health and Human Services and Department of Veterans Affairs for patients with fatal chronic illness.

IN THE HOUSE OF REPRESENTATIVES

JULY 16, 2002

Mr. OBERSTAR introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committees on Ways and Means and Veterans' Affairs, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To amend title XVIII of the Social Security Act to provide certain caregivers with access to Medicare benefits, to amend the Internal Revenue Code of 1986 to provide a long-term care tax credit, and to provide for programs within the Department of Health and Human Services and Department of Veterans Affairs for patients with fatal chronic illness.

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; TABLE OF CONTENTS.**

2 (a) SHORT TITLE.—This Act may be cited as the
3 “Living Well with Fatal Chronic Illness Act of 2002”.

4 (b) TABLE OF CONTENTS.—The table of contents of
5 this Act is as follows:

Sec. 1. Short title; table of contents.

Sec. 2. Access to medicare benefits for certain caregivers 55-to-65 years of age.

Sec. 3. Long-term care tax credit.

Sec. 4. Department of Health and Human Services programs for patients with
fatal chronic illnesses.

Sec. 5. Programs through Department of Veterans Affairs regarding patients
with fatal chronic illnesses.

6 **SEC. 2. ACCESS TO MEDICARE BENEFITS FOR CERTAIN**
7 **CAREGIVERS 55-TO-65 YEARS OF AGE.**

8 (a) IN GENERAL.—Title XVIII of the Social Security
9 Act is amended—

10 (1) by redesignating section 1859 and part D
11 as section 1858 and part E, respectively; and

12 (2) by inserting after such section the following
13 new part:

14 “PART D—PURCHASE OF MEDICARE BENEFITS BY
15 CERTAIN CAREGIVERS AGE 55-TO-65 YEARS OF AGE
16 **“SEC. 1859. PROGRAM BENEFITS; ELIGIBILITY.**

17 “(a) GENERAL DESCRIPTION OF PROGRAM.—This
18 part provides a program of medicare eligibility for those
19 age 55 or older who are caring on a full-time basis for
20 family members and who are not otherwise eligible for
21 group health insurance coverage.

1 “(b) ENTITLEMENT TO MEDICARE BENEFITS FOR
2 ENROLLED INDIVIDUALS.—

3 “(1) IN GENERAL.—An individual enrolled
4 under this part is entitled to the same benefits
5 under this title as an individual entitled to benefits
6 under part A and enrolled under part B.

7 “(2) DEFINITIONS.—For purposes of this part:

8 “(A) FEDERAL OR STATE COBRA CONTINU-
9 ATION PROVISION.—The term ‘Federal or State
10 COBRA continuation provision’ has the mean-
11 ing given the term ‘COBRA continuation provi-
12 sion’ in section 2791(d)(4) of the Public Health
13 Service Act and includes a comparable State
14 program, as determined by the Secretary.

15 “(B) FEDERAL HEALTH INSURANCE PRO-
16 GRAM DEFINED.—The term ‘Federal health in-
17 surance program’ means any of the following:

18 “(i) MEDICARE.—Part A or part B of
19 this title (other than by reason of this
20 part).

21 “(ii) MEDICAID.—A State plan under
22 title XIX.

23 “(iii) FEHBP.—The Federal employ-
24 ees health benefit program under chapter
25 89 of title 5, United States Code.

1 “(iv) TRICARE.—The TRICARE
2 program (as defined in section 1072(7) of
3 title 10, United States Code).

4 “(v) ACTIVE DUTY MILITARY.—Health
5 benefits under title 10, United States
6 Code, to an individual as a member of the
7 uniformed services of the United States.

8 “(C) GROUP HEALTH PLAN.—The term
9 ‘group health plan’ has the meaning given such
10 term in section 2791(a)(1) of the Public Health
11 Service Act.

12 “(D) FAMILY MEMBER.—The term ‘family
13 member’ includes a domestic partner or other
14 significant relationship recognized under law in
15 the State in which the person being cared for
16 resides.

17 “(c) ELIGIBILITY.—An individual who meets the fol-
18 lowing requirements with respect to a month is eligible to
19 enroll under this part with respect to such month:

20 “(1) AGE.—As of the last day of the month, the
21 individual has attained 55 years of age, but has not
22 attained 65 years of age.

23 “(2) MEDICARE ELIGIBILITY (BUT FOR AGE).—
24 The individual would be eligible for benefits under

1 part A or part B for the month if the individual
2 were 65 years of age.

3 “(3) NOT ELIGIBLE FOR COVERAGE UNDER
4 GROUP HEALTH PLANS OR FEDERAL HEALTH INSUR-
5 ANCE PROGRAMS.—The individual is not eligible for
6 benefits or coverage under a Federal health insur-
7 ance program (as defined in subsection (b)(2)(B)) or
8 under a group health plan (other than such eligi-
9 bility merely through a Federal or State COBRA
10 continuation provision) as of the last day of the
11 month involved.

12 “(4) CAREGIVER.—The individual is providing
13 the majority of care to a family member who—

14 “(A) is entitled to benefits under part A,
15 or enrolled under part B; and

16 “(B) requires substantial supervision due
17 to severe cognitive impairment or is unable to
18 perform at least 2 activities of daily living.

19 “(5) LIMITATION OF 1 CAREGIVER FOR EACH
20 DISABLED ELIGIBLE BENEFICIARY.—There is no
21 other individual who is enrolled (or enrolling) under
22 this section on the basis of care provided to the fam-
23 ily member described in paragraph (4).

1 **“SEC. 1859A. ENROLLMENT PROCESS; COVERAGE.**

2 “(a) IN GENERAL.—An individual may enroll in the
3 program established under this part only in such manner
4 and form as may be prescribed by regulations, and only
5 during an enrollment period prescribed by the Secretary
6 consistent with the provisions of this section. Such regula-
7 tions shall provide a process under which individuals eligi-
8 ble to enroll as of a month are permitted to pre-enroll dur-
9 ing a prior month within an enrollment period described
10 in subsection (b).

11 “(b) ENROLLMENT PERIODS.—

12 “(1) IN GENERAL.—In the case of individuals
13 eligible to enroll under this part under section
14 1859(c)—

15 “(A) INDIVIDUALS ELIGIBLE AT TIME PRO-
16 GRAM BEGINS.—If the individual is eligible to
17 enroll under such section for January 2003, the
18 enrollment period shall begin on November 1,
19 2002, and shall end on February 28, 2003. Any
20 such enrollment before January 1, 2003, is con-
21 ditioned upon compliance with the conditions of
22 eligibility for January 2003.

23 “(B) INDIVIDUALS WHO BECOME ELIGIBLE
24 LATER.—If the individual becomes eligible to
25 enroll under such section for a month after
26 January 2003, the enrollment period shall be

1 the 4-month period beginning on the first day
2 of the second month before the month in which
3 the individual first is eligible to so enroll. Any
4 such enrollment before the first day of the third
5 month of such enrollment period is conditioned
6 upon compliance with the conditions of eligi-
7 bility for such third month.

8 “(2) AUTHORITY TO CORRECT FOR GOVERN-
9 MENT ERRORS.—The provisions of section 1837(h)
10 apply with respect to enrollment under this part in
11 the same manner as they apply to enrollment under
12 part B.

13 “(c) DATE COVERAGE BEGINS.—

14 “(1) IN GENERAL.—The period during which
15 an individual is entitled to benefits under this part
16 shall begin as follows, but in no case earlier than
17 January 1, 2003:

18 “(A) In the case of an individual who en-
19 rolls (including pre-enrolls) before the month in
20 which the individual satisfies eligibility for en-
21 rollment under section 1859, the first day of
22 such month of eligibility.

23 “(B) In the case of an individual who en-
24 rolls during or after the month in which the in-
25 dividual first satisfies eligibility for enrollment

1 under such section, the first day of the fol-
2 lowing month.

3 “(2) AUTHORITY TO PROVIDE FOR PARTIAL
4 MONTHS OF COVERAGE.—Under regulations, the
5 Secretary may, in the Secretary’s discretion, provide
6 for coverage periods that include portions of a
7 month in order to avoid lapses of coverage.

8 “(3) LIMITATION ON PAYMENTS.—No payments
9 may be made under this title with respect to the ex-
10 penses of an individual enrolled under this part un-
11 less such expenses were incurred by such individual
12 during a period which, with respect to the individual,
13 is a coverage period under this section.

14 “(d) TERMINATION OF COVERAGE.—

15 “(1) IN GENERAL.—An individual’s coverage
16 period under this part shall continue until the indi-
17 vidual’s enrollment has been terminated at the ear-
18 liest of the following:

19 “(A) GENERAL PROVISIONS.—

20 “(i) NOTICE.—The individual files no-
21 tice (in a form and manner prescribed by
22 the Secretary) that the individual no
23 longer wishes to participate in the insur-
24 ance program under this part.

1 “(ii) NONPAYMENT OF PREMIUMS.—

2 The individual fails to make payment of
3 premiums required for enrollment under
4 this part.

5 “(iii) MEDICARE ELIGIBILITY.—The
6 individual becomes entitled to benefits
7 under part A or enrolled under part B
8 (other than by reason of this part).

9 “(B) TERMINATION BASED ON AGE.—The
10 individual attains 65 years of age.

11 “(C) OBTAINING ACCESS TO EMPLOYMENT-
12 BASED COVERAGE OR FEDERAL HEALTH INSUR-
13 ANCE PROGRAM.—The individual is covered (or
14 eligible for coverage) as a participant or bene-
15 ficiary under a group health plan or under a
16 Federal health insurance program.

17 “(D) TERMINATION OF CAREGIVING.—One
18 year after the date that the individual ceases to
19 be providing the caregiving described in section
20 1859(c)(4) for a period of 4 consecutive weeks.

21 “(2) EFFECTIVE DATE OF TERMINATION.—

22 “(A) NOTICE.—The termination of a cov-
23 erage period under paragraph (1)(A)(i) shall
24 take effect at the close of the month following
25 the month in which the notice is filed.

1 “(B) NONPAYMENT OF PREMIUM.—The
2 termination of a coverage period under para-
3 graph (1)(A)(ii) shall take effect on a date de-
4 termined under regulations, which may be de-
5 termined so as to provide a grace period in
6 which overdue premiums may be paid and cov-
7 erage continued. The grace period determined
8 under the preceding sentence shall not exceed
9 60 days; except that it may be extended for an
10 additional 30 days in any case where the Sec-
11 retary determines that there was good cause for
12 failure to pay the overdue premiums within
13 such 60-day period.

14 “(C) AGE OR MEDICARE ELIGIBILITY.—
15 The termination of a coverage period under
16 paragraph (1)(A)(iii) or (1)(B) shall take effect
17 as of the first day of the month in which the
18 individual attains 65 years of age or becomes
19 entitled to benefits under part A or enrolled for
20 benefits under part B (other than by reason of
21 this part).

22 “(D) ACCESS TO COVERAGE.—The termi-
23 nation of a coverage period under paragraph
24 (1)(C) shall take effect on the date on which
25 the individual is eligible to begin a period of

1 creditable coverage (as defined in section
2 2701(c) of the Public Health Service Act)
3 under a group health plan or under a Federal
4 health insurance program.

5 **“SEC. 1859B. PREMIUMS.**

6 “(a) AMOUNT OF MONTHLY PREMIUMS.—The Sec-
7 retary shall, during September of each year (beginning
8 with 2002), determine a premium rate which shall apply
9 with respect to coverage provided under this title for any
10 month in the succeeding year. Such rate for individuals
11 residing in a premium area for most of any month in a
12 year shall be equal to $\frac{1}{12}$ of the average, annual per capita
13 amount estimated under subsection (b)(1) for the year,
14 adjusted for such area under subsection (b)(2).

15 “(b) ANNUAL PREMIUM.—

16 “(1) NATIONAL, PER CAPITA AVERAGE.—The
17 Secretary shall estimate the average, annual per
18 capita amount that would be payable under this title
19 with respect to individuals residing in the United
20 States who meet the requirement of section
21 1859(c)(1) as if all such individuals were eligible for
22 (and enrolled) under this title during the entire year
23 (and assuming that section 1862(b)(2)(A)(i) did not
24 apply).

1 “(2) GEOGRAPHIC ADJUSTMENT.—The Sec-
2 retary shall adjust the amount determined under
3 paragraph (1) for each premium area (specified
4 under subsection (c)) in order to take into account
5 such factors as the Secretary deems appropriate and
6 shall limit the maximum premium under this para-
7 graph in a premium area to assure participation in
8 all areas throughout the United States.

9 “(c) ESTABLISHMENT OF PREMIUM AREAS.—For
10 purposes of this part, the term ‘premium area’ means such
11 an area as the Secretary shall specify to carry out this
12 part. The Secretary from time to time may change the
13 boundaries of such premium areas. The Secretary shall
14 seek to minimize the number of such areas specified under
15 this paragraph.

16 **“SEC. 1859C. PAYMENT OF PREMIUMS.**

17 “(a) PAYMENT OF MONTHLY PREMIUM.—

18 “(1) IN GENERAL.—The Secretary shall provide
19 for payment and collection of the monthly premium,
20 determined under section 1859B(a) for the premium
21 area in which the individual principally resides, in
22 the same manner as for payment of monthly pre-
23 miums under section 1840, except that, for purposes
24 of applying this section, any reference in such sec-
25 tion to the Federal Supplementary Medical Insur-

1 ance Trust Fund is deemed a reference to the Trust
2 Fund established under section 1859D.

3 “(2) PERIOD OF PAYMENT.—In the case of an
4 individual who participates in the program estab-
5 lished by this title, the monthly premium shall be
6 payable for the period commencing with the first
7 month of the individual’s coverage period and ending
8 with the month in which the individual’s coverage
9 under this title terminates.

10 “(b) APPLICATION OF CERTAIN PROVISIONS.—The
11 provisions of section 1840 (other than subsection (h))
12 shall apply to premiums collected under this section in the
13 same manner as they apply to premiums collected under
14 part B, except that any reference in such section to the
15 Federal Supplementary Medical Insurance Trust Fund is
16 deemed a reference to the Trust Fund established under
17 section 1859D.

18 **“SEC. 1859D. MEDICARE CAREGIVER TRUST FUND.**

19 “(a) ESTABLISHMENT OF TRUST FUND.—

20 “(1) IN GENERAL.—There is hereby created on
21 the books of the Treasury of the United States a
22 trust fund to be known as the ‘Medicare Caregiver
23 Trust Fund’ (in this section referred to as the
24 ‘Trust Fund’). The Trust Fund shall consist of such
25 gifts and bequests as may be made as provided in

1 section 201(i)(1) and such amounts as may be de-
2 posited in, or appropriated to, such fund as provided
3 in this title.

4 “(2) PREMIUMS.—Premiums collected under
5 section 1859B shall be transferred to the Trust
6 Fund.

7 “(b) INCORPORATION OF PROVISIONS.—

8 “(1) IN GENERAL.—Subject to paragraph (2),
9 subsections (b) through (i) of section 1841 shall
10 apply with respect to the Trust Fund and this title
11 in the same manner as they apply with respect to
12 the Federal Supplementary Medical Insurance Trust
13 Fund and part B, respectively.

14 “(2) MISCELLANEOUS REFERENCES.—In apply-
15 ing provisions of section 1841 under paragraph
16 (1)—

17 “(A) any reference in such section to ‘this
18 part’ is construed to refer to this part D;

19 “(B) any reference in section 1841(h) to
20 section 1840(d) and in section 1841(i) to sec-
21 tions 1840(b)(1) and 1842(g) are deemed ref-
22 erences to comparable authority exercised under
23 this part; and

24 “(C) payments may be made under section
25 1841(g) to the Trust Funds under sections

1 1817 and 1841 as reimbursement to such funds
2 for payments they made for benefits provided
3 under this part.

4 **“SEC. 1859E. OVERSIGHT AND ACCOUNTABILITY.**

5 “(a) THROUGH ANNUAL REPORTS OF TRUSTEES.—
6 The Board of Trustees of the Medicare Caregiver Trust
7 Fund under section 1859D(b)(1) shall report on an an-
8 nual basis to Congress concerning the status of the Trust
9 Fund and the need for adjustments in the program under
10 this part to maintain financial solvency of the program
11 under this part.

12 “(b) PERIODIC GAO REPORTS.—The Comptroller
13 General of the United States shall periodically submit to
14 Congress reports on the adequacy of the financing of cov-
15 erage provided under this part. The Comptroller General
16 shall include in such report such recommendations for ad-
17 justments in such financing and coverage as the Comp-
18 troller General deems appropriate in order to maintain fi-
19 nancial solvency of the program under this part.

20 **“SEC. 1859F. ADMINISTRATION AND MISCELLANEOUS.**

21 “(a) TREATMENT FOR PURPOSES OF TITLE.—Ex-
22 cept as otherwise provided in this part—

23 “(1) individuals enrolled under this part shall
24 be treated for purposes of this title as though the in-

1 dividual were entitled to benefits under part A and
2 enrolled under part B; and

3 “(2) benefits described in section 1859 shall be
4 payable under this title to such individuals in the
5 same manner as if such individuals were so entitled
6 and enrolled.

7 “(b) NOT TREATED AS MEDICARE PROGRAM FOR
8 PURPOSES OF MEDICAID PROGRAM.—For purposes of ap-
9 plying title XIX (including the provision of medicare cost-
10 sharing assistance under such title), an individual who is
11 enrolled under this part shall not be treated as being enti-
12 tled to benefits under this title.

13 “(c) NOT TREATED AS MEDICARE PROGRAM FOR
14 PURPOSES OF COBRA CONTINUATION PROVISIONS.—In
15 applying a COBRA continuation provision (as defined in
16 section 2791(d)(4) of the Public Health Service Act), any
17 reference to an entitlement to benefits under this title
18 shall not be construed to include entitlement to benefits
19 under this title pursuant to the operation of this part.”.

20 (b) CONFORMING AMENDMENTS TO SOCIAL SECUR-
21 ITY ACT PROVISIONS.—

22 (1) Section 201(i)(1) of the Social Security Act
23 (42 U.S.C. 401(i)(1)) is amended by striking “or the
24 Federal Supplementary Medical Insurance Trust
25 Fund” and inserting “the Federal Supplementary

1 Medical Insurance Trust Fund, and the Medicare
2 Caregiver Trust Fund”.

3 (2) Section 201(g)(1)(A) of such Act (42
4 U.S.C. 401(g)(1)(A)) is amended by striking “and
5 the Federal Supplementary Medical Insurance Trust
6 Fund established by title XVIII” and inserting “,
7 the Federal Supplementary Medical Insurance Trust
8 Fund, and the Medicare Caregiver Trust Fund es-
9 tablished by title XVIII”.

10 (3) Section 1820(i) of such Act (42 U.S.C.
11 1395i-4(i)) is amended by striking “part D” and in-
12 serting “part E”.

13 (4) Part C of title XVIII of such Act is
14 amended—

15 (A) in section 1851(a)(2)(B) (42 U.S.C.
16 1395w-21(a)(2)(B)), by striking “1859(b)(3)”
17 and inserting “1858(b)(3)”;

18 (B) in section 1851(a)(2)(C) (42 U.S.C.
19 1395w-21(a)(2)(C)), by striking “1859(b)(2)”
20 and inserting “1858(b)(2)”;

21 (C) in section 1852(a)(1) (42 U.S.C.
22 1395w-22(a)(1)), by striking “1859(b)(3)” and
23 inserting “1858(b)(3)”;

24 (D) in section 1852(a)(3)(B)(ii) (42
25 U.S.C. 1395w-22(a)(3)(B)(ii)), by striking

1 “1859(b)(2)(B)” and inserting
 2 “1858(b)(2)(B)”;

3 (E) in section 1853(a)(1)(A) (42 U.S.C.
 4 1395w-23(a)(1)(A)), by striking “1859(e)(4)”
 5 and inserting “1858(e)(4)”; and

6 (F) in section 1853(a)(3)(D) (42 U.S.C.
 7 1395w-23(a)(3)(D)), by striking “1859(e)(4)”
 8 and inserting “1858(e)(4)”.

9 (5) Section 1853(c) of such Act (42 U.S.C.
 10 1395w-23(c)) is amended—

11 (A) in paragraph (1), by striking “or (7)”
 12 and inserting “, (7), or (8)”, and

13 (B) by adding at the end the following:

14 “(8) ADJUSTMENT FOR CAREGIVER ACCESS.—

15 In applying this subsection with respect to individ-
 16 uals entitled to benefits under part D, the Secretary
 17 shall provide for an appropriate adjustment in the
 18 Medicare+Choice capitation rate as may be appro-
 19 priate to reflect differences between the population
 20 served under such part and the population under
 21 parts A and B.”.

22 (c) OTHER CONFORMING AMENDMENTS.—

23 (1) Section 138(b)(4) of the Internal Revenue
 24 Code of 1986 is amended by striking “1859(b)(3)”
 25 and inserting “1858(b)(3)”.

1 (2)(A) Section 602(2)(D)(ii) of the Employee
 2 Retirement Income Security Act of 1974 (29 U.S.C.
 3 1162(2)) is amended by inserting “(not including an
 4 individual who is so entitled pursuant to enrollment
 5 under section 1859A)” after “Social Security Act”.

6 (B) Section 2202(2)(D)(ii) of the Public Health
 7 Service Act (42 U.S.C. 300bb–2(2)(D)(ii)) is amend-
 8 ed by inserting “(not including an individual who is
 9 so entitled pursuant to enrollment under section
 10 1859A)” after “Social Security Act”.

11 (C) Section 4980B(f)(2)(B)(i)(V) of the Inter-
 12 nal Revenue Code of 1986 is amended by inserting
 13 “(not including an individual who is so entitled pur-
 14 suant to enrollment under section 1859A)” after
 15 “Social Security Act”.

16 **SEC. 3. LONG-TERM CARE TAX CREDIT.**

17 (a) IN GENERAL.—Subpart A of part IV of sub-
 18 chapter A of chapter 1 of the Internal Revenue Code of
 19 1986 (relating to nonrefundable personal credits) is
 20 amended by inserting after section 25B the following new
 21 section:

22 **“SEC. 25C. LONG-TERM CARE TAX CREDIT.**

23 “(a) ALLOWANCE OF CREDIT.—There shall be al-
 24 lowed as a credit against the tax imposed by this chapter
 25 for the taxable year an amount equal to \$3,000 multiplied

1 by the number of applicable individuals with respect to
2 whom the taxpayer is an eligible caregiver for the taxable
3 year.

4 “(b) LIMITATION BASED ON ADJUSTED GROSS IN-
5 COME.—

6 “(1) IN GENERAL.—The amount of the credit
7 allowable under subsection (a) shall be reduced (but
8 not below zero) by \$50 for each \$1,000 (or fraction
9 thereof) by which the taxpayer’s modified adjusted
10 gross income (as defined in section 24(b)(1)) exceeds
11 the threshold amount (as defined in section
12 24(b)(2)).

13 “(2) LIMITATION BASED ON AMOUNT OF
14 TAX.—The credit allowed under subsection (a) for
15 any taxable year shall not exceed the excess of—

16 “(A) the sum of the regular tax liability
17 (as defined in section 26(b)) plus the tax im-
18 posed by section 55, over

19 “(B) the sum of the credits allowable
20 under this subpart (other than this section and
21 sections 23 and 25B) and section 27 for the
22 taxable year.

23 “(c) DEFINITIONS.—For purposes of this section—

24 “(1) APPLICABLE INDIVIDUAL.—

1 “(A) IN GENERAL.—The term ‘applicable
2 individual’ means, with respect to any taxable
3 year, any individual who has been certified, be-
4 fore the due date for filing the return of tax for
5 the taxable year (without extensions), by a phy-
6 sician (as defined in section 1861(r)(1) of the
7 Social Security Act) as being an individual with
8 long-term care needs described in subparagraph
9 (B) for a period—

10 “(i) which is at least 180 consecutive
11 days, and

12 “(ii) a portion of which occurs within
13 the taxable year.

14 Such term shall not include any individual oth-
15 erwise meeting the requirements of the pre-
16 ceding sentence unless within the 39½ month
17 period ending on such due date (or such other
18 period as the Secretary prescribes) a physician
19 (as so defined) has certified that such indi-
20 vidual meets such requirements.

21 “(B) INDIVIDUALS WITH LONG-TERM CARE
22 NEEDS.—An individual is described in this sub-
23 paragraph if the individual meets any of the fol-
24 lowing requirements:

1 “(i) The individual is at least 6 years
2 of age and—

3 “(I) is unable to perform (with-
4 out substantial assistance from an-
5 other individual) at least 3 activities
6 of daily living (as defined in section
7 7702B(c)(2)(B)) due to a lack of
8 functional capacity, or

9 “(II) requires substantial super-
10 vision to protect such individual from
11 threats to health and safety due to se-
12 vere cognitive impairment and is un-
13 able to perform at least 1 activity of
14 daily living (as so defined) or to the
15 extent provided in regulations pre-
16 scribed by the Secretary (in consulta-
17 tion with the Secretary of Health and
18 Human Services), is unable to engage
19 in age appropriate activities.

20 “(ii) The individual is at least 2 but
21 not 6 years of age and is unable due to a
22 loss of functional capacity to perform
23 (without substantial assistance from an-
24 other individual) at least 2 of the following
25 activities: eating, transferring, or mobility.

1 “(iii) The individual is under 2 years
2 of age and requires specific durable med-
3 ical equipment by reason of a severe health
4 condition or requires a skilled practitioner
5 trained to address the individual’s condi-
6 tion to be available if the individual’s par-
7 ents or guardians are absent.

8 “(2) ELIGIBLE CAREGIVER.—

9 “(A) IN GENERAL.—A taxpayer shall be
10 treated as an eligible caregiver for any taxable
11 year with respect to the following individuals:

12 “(i) The taxpayer.

13 “(ii) The taxpayer’s spouse.

14 “(iii) An individual with respect to
15 whom the taxpayer is allowed a deduction
16 under section 151 for the taxable year.

17 “(iv) An individual who would be de-
18 scribed in clause (iii) for the taxable year
19 if section 151(c)(1)(A) were applied by
20 substituting for the exemption amount an
21 amount equal to 200 percent of the pov-
22 erty level determined by using criteria of
23 poverty established by the Bureau of the
24 Census.

1 “(v) An individual who would be de-
2 scribed in clause (iii) for the taxable year
3 if—

4 “(I) the requirements of clause
5 (iv) are met with respect to the indi-
6 vidual, and

7 “(II) the requirements of sub-
8 paragraph (B) are met with respect to
9 the individual in lieu of the support
10 test of section 152(a).

11 “(B) RESIDENCY TEST.—The require-
12 ments of this subparagraph are met if an indi-
13 vidual has as his principal place of abode the
14 home of the taxpayer and—

15 “(i) in the case of an individual who
16 is an ancestor or descendant of the tax-
17 payer or the taxpayer’s spouse, is a mem-
18 ber of the taxpayer’s household for over
19 half the taxable year, or

20 “(ii) in the case of any other indi-
21 vidual, is a member of the taxpayer’s
22 household for the entire taxable year.

23 “(C) SPECIAL RULES WHERE MORE THAN
24 1 ELIGIBLE CAREGIVER.—

1 “(i) IN GENERAL.—If more than 1 in-
2 dividual is an eligible caregiver with re-
3 spect to the same applicable individual for
4 taxable years ending with or within the
5 same calendar year, a taxpayer shall be
6 treated as the eligible caregiver if each
7 such individual (other than the taxpayer)
8 files a written declaration (in such form
9 and manner as the Secretary may pre-
10 scribe) that such individual will not claim
11 such applicable individual for the credit
12 under this section.

13 “(ii) NO AGREEMENT.—If each indi-
14 vidual required under clause (i) to file a
15 written declaration under clause (i) does
16 not do so, the individual with the highest
17 modified adjusted gross income (as defined
18 in section 32(c)(5)) shall be treated as the
19 eligible caregiver.

20 “(iii) MARRIED INDIVIDUALS FILING
21 SEPARATELY.—In the case of married indi-
22 viduals filing separately, the determination
23 under this subparagraph as to whether the
24 husband or wife is the eligible caregiver
25 shall be made under the rules of clause (ii)

1 (whether or not one of them has filed a
2 written declaration under clause (i)).

3 “(d) IDENTIFICATION REQUIREMENT.—No credit
4 shall be allowed under this section to a taxpayer with re-
5 spect to any applicable individual unless the taxpayer in-
6 cludes the name and taxpayer identification number of
7 such individual, and the identification number of the phy-
8 sician certifying such individual, on the return of tax for
9 the taxable year.

10 “(e) TAXABLE YEAR MUST BE FULL TAXABLE
11 YEAR.—Except in the case of a taxable year closed by rea-
12 son of the death of the taxpayer, no credit shall be allow-
13 able under this section in the case of a taxable year cov-
14 ering a period of less than 12 months.”.

15 (b) CONFORMING AMENDMENTS.—

16 (1) Paragraph (1) of section 26(a) of such Code
17 is amended by striking “and 25B” and inserting
18 “25B, and 25C”.

19 (2) Paragraph (2) of section 6213(g) of such
20 Code is amended by striking “and” at the end of
21 subparagraph (L), by striking the period at the end
22 of subparagraph (M) and inserting “, and”, and by
23 inserting after subparagraph (M) the following new
24 subparagraph:

1 “(N) an omission of a correct TIN or phy-
 2 sician identification required under section
 3 25C(d) (relating to long-term care tax credit) to
 4 be included on a return.”

5 (3) The table of sections for subpart A of part
 6 IV of subchapter A of chapter 1 of such Code is
 7 amended by inserting after the item relating to sec-
 8 tion 25B the following new item:

 “Sec. 25C. Long-term care tax credit.”.

9 (c) EFFECTIVE DATE.—The amendments made by
 10 this section shall apply to taxable years beginning after
 11 December 31, 2002.

12 **SEC. 4. DEPARTMENT OF HEALTH AND HUMAN SERVICES**
 13 **PROGRAMS FOR PATIENTS WITH FATAL**
 14 **CHRONIC ILLNESSES.**

15 (a) ESTABLISHMENT OF PROGRAMS.—The Secretary
 16 of Health and Human Services shall carry out research,
 17 demonstration, and education programs with respect to
 18 fatal chronic illness through the Public Health Service.

19 (b) STUDIES ON END-OF-LIFE CARE.—The Sec-
 20 retary shall conduct studies on end-of-life care through all
 21 relevant agencies and through the Assistant Secretary for
 22 Planning and Evaluation. Such studies shall include an
 23 examination of the development of practice parameters ap-
 24 plicable to such care as well as research regarding such
 25 care. Such studies shall also include an annual report from

1 the Secretary to the appropriate committees for oversight
2 in Congress and to the Special Committee on Aging in
3 the Senate on service delivery and quality of life for per-
4 sons living through fatal chronic illness and their families
5 and professional caregivers.

6 (c) HEALTH RESOURCES AND SERVICES ADMINIS-
7 TRATION.—

8 (1) IN GENERAL.—In carrying out subsection
9 (a), the Secretary, acting through the Administrator
10 of the Health Resources and Services Administra-
11 tion, shall carry out research, demonstration, and
12 education programs toward improving the delivery of
13 appropriate health and support services for patients
14 with fatal chronic illnesses.

15 (2) HEALTH CENTERS.—As determined appro-
16 priate by the Secretary, paragraph (1) may be car-
17 ried out through the program under section 330 of
18 the Public Health Service Act (relating to commu-
19 nity and migrant health centers and health centers
20 regarding homeless individuals and residents of pub-
21 lic housing), including by designating individuals
22 with fatal chronic illnesses as medically underserved
23 populations.

24 (3) CAREGIVERS.—Programs under paragraph
25 (1) shall include activities regarding appropriate

1 support services for caregivers for patients with fatal
2 chronic illness, including respite care.

3 (4) HEALTH PROFESSIONS TRAINING.—Pro-
4 grams under paragraph (1) shall include making
5 awards of grants or contracts to public and non-
6 profit private entities for the purpose of training
7 health professionals, including students attending
8 health professions schools, in the care of patients
9 with fatal chronic illnesses. Such training shall in-
10 clude training in the provision of appropriate pallia-
11 tive care and appropriate referral to hospices, and
12 training provided as continuing education.

13 (5) INITIATIVE.—Programs under paragraph
14 (1) shall include an initiative to coordinate innova-
15 tion, evaluation, and service delivery relating to fatal
16 chronic illnesses.

17 (d) AGENCY FOR HEALTHCARE RESEARCH AND
18 QUALITY.—

19 (1) IN GENERAL.—In carrying out section
20 912(c) of the Public Health Service Act, the Sec-
21 retary, acting through the Director of the Agency
22 for Healthcare Research and Quality, shall, with re-
23 spect to patients with fatal chronic illnesses—

24 (A) identify the causes of preventable
25 health care errors and patient injury in health

1 care delivery, including errors of inadequate
2 mobilization of services to the home, inadequate
3 continuity of caregivers, inadequate symptom
4 prevention, management, and relief, or inad-
5 equate advance care planning;

6 (B) develop, demonstrate, and evaluate
7 strategies for reliable performance of the care
8 system, including reducing errors and improv-
9 ing patient safety and health outcomes; and

10 (C) disseminate such effective strategies
11 throughout the health care industry.

12 (2) GRANTS.—In carrying out paragraph
13 (1)(A), the Secretary shall make grants for the pur-
14 pose of developing reliable and current data and in-
15 sight as to the merits and efficiencies of various
16 strategies for providing health care, including pallia-
17 tive and hospice care, and social services for patients
18 with fatal chronic illnesses.

19 (e) CENTERS FOR DISEASE CONTROL AND PREVEN-
20 TION.—The Director of the Centers for Disease Control
21 and Prevention shall expand activities with respect to epi-
22 demiology and public health in fatal chronic illness. Such
23 activities may include contracting with the Institute of
24 Medicine or another national interest non-profit organiza-
25 tion to provide a review of the status of care for the end

1 of life, which review shall be included by the Secretary in
2 the annual reports to Congress under subsection (h).

3 (f) NATIONAL INSTITUTES OF HEALTH.—

4 (1) EXPANSION OF ACTIVITIES.—The Director
5 of the National Institutes of Health (in this sub-
6 section referred to as the “Director”) shall expand,
7 intensify, and coordinate the activities of the Na-
8 tional Institutes of Health with respect to research
9 on fatal chronic illness. Such activities shall include
10 programs, requests for proposals, study section
11 membership, advisory council membership, and
12 training programs to support rapid and substantial
13 improvements in understanding—

14 (A) mechanisms of disability and suffering
15 in fatal chronic illness and the relief and man-
16 agement of that disability and suffering
17 through to end of life; and

18 (B) human resources, service delivery ar-
19 rangements, technology, and financing that
20 would be most useful in ensuring comfort and
21 dignity for individuals with fatal chronic illness,
22 and in relieving the burden for family and pro-
23 fessional caregivers.

24 (2) ADMINISTRATION.—The Director shall
25 carry out this subsection acting through the Direc-

1 tors of every Institute within the National Institutes
2 of Health that has at least one fatal chronic illness
3 in its purview.

4 (3) COLLABORATION.—In carrying out this sub-
5 section, the Director of the National Institutes of
6 Health shall collaborate with the Department of Vet-
7 erans Affairs, the Agency for Healthcare Research
8 and Quality, and any other agency that the Director
9 determines appropriate. The Secretary of Veterans
10 Affairs and the Director of the Agency for
11 Healthcare Research and Quality shall assist in such
12 collaboration.

13 (4) RESPONSIBILITIES OF INSTITUTES.—Each
14 Institute within the National Institutes of Health
15 that has fatal chronic illness in its purview shall es-
16 tablish a plan for improving understanding of the
17 mechanisms of disability and suffering in fatal
18 chronic illness and the relief and management of
19 that disability and suffering through to end of life.
20 Since most Americans now die of chronic heart or
21 lung failure, cancer, stroke, dementia, or multifacto-
22 rial frailty, each such Institute shall develop and im-
23 plement a strategic plan and a set of projects that
24 aim primarily to ensure that affected patients and

1 their families can live through advanced illness and
2 death comfortably and meaningfully.

3 (5) CENTERS OF EXCELLENCE.—

4 (A) IN GENERAL.—In carrying out para-
5 graph (1), the Director shall make awards of
6 grants and contracts to public or nonprofit pri-
7 vate entities for the establishment and oper-
8 ation of centers of excellence to carry out re-
9 search, demonstration, and education programs
10 regarding fatal chronic illness, including pro-
11 grams regarding palliative care.

12 (B) DESIGNATION.—In carrying out this
13 subsection, the Director shall designate at least
14 2 Claude D. Pepper Older Americans Independ-
15 ence Centers (supported by the National Insti-
16 tute on Aging), 2 program projects of the Na-
17 tional, Heart, Lung, and Blood Institute, and 2
18 comprehensive cancer centers (supported by the
19 National Cancer Institute) to provide education
20 and information support and research data and
21 methods leadership for substantial and rapid
22 improvements in the understanding of the
23 mechanisms of disability and suffering in fatal
24 chronic illness and the relief and management

1 of that disability and suffering through to the
2 end of life.

3 (C) RESEARCH.—Each center established
4 or operated under subparagraph (A) or des-
5 ignated under subparagraph (B) shall conduct
6 basic and clinical research into fatal chronic ill-
7 ness.

8 (D) CERTAIN ACTIVITIES.—The Secretary
9 shall ensure that, with respect to the geographic
10 area in which a center of excellence under sub-
11 paragraph (A) is located, the activities of the
12 center include—

13 (i) providing information and edu-
14 cation regarding fatal chronic illness to
15 health professionals and the public;

16 (ii) serving as a resource through
17 which health professionals, and patients
18 and their caregivers, can plan and coordi-
19 nate the provision of health and support
20 services regarding fatal chronic illness; and

21 (iii) providing training and support of
22 implementation of quality improvement.

23 (g) MEDICARE PILOT PROGRAMS FOR TREATMENT
24 OF FATAL CHRONIC ILLNESSES.—

1 (1) ESTABLISHMENT.—The Secretary, in all
2 relevant parts of the Department of Health and
3 Human Services, including the Centers for Medicare
4 & Medicaid Services and the Office of the Assistant
5 Secretary for Planning and Evaluation, shall provide
6 for pilot programs under this subsection. The pilot
7 programs shall be developed under a coordinated na-
8 tional effort in order to demonstrate innovative, ef-
9 fective means of delivering care to Medicare bene-
10 ficiaries with fatal chronic illnesses under the Medi-
11 care program. The pilot programs shall be completed
12 within 5 years after the date that funds are first ap-
13 propriated under this subsection.

14 (2) DESIGN.—The pilot programs under this
15 subsection shall be designed to learn how—

16 (A) to effectively and efficiently deliver
17 quality care to the fatally chronically ill;

18 (B) to provide and maintain continuity of
19 care for the fatally chronically ill;

20 (C) to provide advance care planning to
21 the fatally chronically ill;

22 (D) to determine what rate and strategies
23 for payment are most appropriate;

24 (E) to deliver emergency care for the fa-
25 tally chronically ill;

1 (F) to facilitate access to hospice care
2 when the Medicare beneficiary becomes eligible
3 for such care;

4 (G) to develop and estimate the effect of
5 potential alternative severity criteria for eligi-
6 bility of specially tailored programs;

7 (H) to test the effectiveness and costs of
8 new strategies for family caregivers support;

9 (I) to implement a clinical services and
10 payment program that uses thresholds of sever-
11 ity to define the onset of the need for com-
12 prehensive end-of-life services;

13 (J) to test the merits of using severity cri-
14 teria (relating to fatal chronic illness) in deter-
15 mining eligibility for the Medicare hospice pro-
16 gram, but only when use of such criteria ex-
17 pands access to hospice care to individuals who
18 are not yet terminally ill (as that term is de-
19 fined at section 1861(dd)(3)(A) of the Social
20 Security Act); and

21 (K) to arrange financial incentives so that
22 substantially diminished payments arise when
23 care providers fail to ensure timely advance
24 care planning, symptom prevention, manage-

1 ment, and relief, or continuity of care across
2 time and settings.

3 (3) CONDUCT OF PILOT PROGRAMS.—The Sec-
4 retary shall conduct pilot programs in at least 6
5 sites and in at least 3 States.

6 (4) REPORT TO CONGRESS.—The Secretary
7 shall submit to Congress a report on the pilot pro-
8 grams under this subsection. Such report shall in-
9 clude recommendations regarding whether the pilot
10 programs should become a permanent part of the
11 Medicare program.

12 (h) ANNUAL REPORTS.—The Secretary, in consulta-
13 tion with the Secretary of Veterans Affairs and other ap-
14 propriate Federal agencies, shall submit an annual report
15 to Congress on end-of-life care and on the research, dem-
16 onstration, and education programs and studies conducted
17 under this section. The Centers for Disease Control and
18 Prevention shall be the lead agency for integrating and
19 preparing the annual reports under this subsection unless
20 the Secretary designates otherwise.

21 (i) DEFINITIONS.—For purposes of this section:

22 (1) The term “fatal chronic illness” means a
23 disease (or diseases), condition (or conditions), or
24 disorder (or disorders) that ordinarily worsens and
25 causes death and that causes a physical or mental

1 disability or periodic episodes of significant loss of
2 functional capacity.

3 (2) The term “Secretary” means the Secretary
4 of Health and Human Services.

5 (j) AUTHORIZATION OF APPROPRIATIONS.—There
6 are authorized to be appropriated—

7 (1) such sums as may be necessary to carry out
8 subsections (a), (b), (e), and (f);

9 (2) \$50,000,000 for the 5-fiscal-year period (be-
10 ginning with fiscal year 2004) to carry out sub-
11 section (c), excluding paragraph (5) of that sub-
12 section;

13 (3) \$100,000,000 for the 3-fiscal-year period
14 (beginning with fiscal year 2004) to carry out sub-
15 section (c)(5);

16 (4) \$20,000,000 for the 5-fiscal-year period (be-
17 ginning with fiscal year 2004) to carry out sub-
18 section (d);

19 (5) to carry out subsection (g) for each of fiscal
20 years 2003 through 2007—

21 (A) \$50,000,000 for the purposes of con-
22 ducting evaluations of pilot programs; and

23 (B) \$50,000,000 for the purpose of pro-
24 viding clinical services under pilot programs;
25 and

1 (6) \$500,000 for each fiscal year during the 5-
2 fiscal-year period beginning with fiscal year 2004 to
3 carry out subsection (h).

4 **SEC. 5. PROGRAMS THROUGH DEPARTMENT OF VETERANS**
5 **AFFAIRS REGARDING PATIENTS WITH FATAL**
6 **CHRONIC ILLNESSES.**

7 (a) IN GENERAL.—(1) Chapter 73 of title 38, United
8 States Code, is amended by adding at the end of sub-
9 chapter II the following new section:

10 **“§ 7324. Programs for patients with fatal chronic ill-**
11 **nesses**

12 “(a) ESTABLISHMENT OF PROGRAMS.—(1) The Sec-
13 retary shall develop and carry out programs to improve
14 the delivery of appropriate health and support services for
15 patients with fatal chronic illnesses. As part of such pro-
16 grams, the Secretary shall seek to develop services in col-
17 laboration with community service providers serving popu-
18 lations of persons other than veterans, especially those
19 populations that use the Medicare program.

20 “(2) For purposes of this section, community service
21 providers are entities outside the Department that provide
22 health care services to persons in the communities in
23 which they are located.

24 “(b) ROLE OF GRECCs AND HEALTH SERVICES RE-
25 SEARCH.—The Secretary shall take appropriate steps to

1 involve in programs under this section both geriatric re-
2 search, education, and clinical centers under section 7314
3 of this title and activities of Health Services research and
4 quality improvement initiatives of the Department. As
5 part of such steps, the Secretary shall seek to target the
6 work of such centers and initiatives to improve care for
7 veterans with fatal chronic illnesses.

8 “(c) TRAINING.—In conducting programs of profes-
9 sional training and staff development for health-care per-
10 sonnel of the Department and persons being trained
11 through health-care programs conducted by the Secretary,
12 the Secretary shall ensure that such programs include
13 training in pain relief and end-of-life care for persons with
14 fatal chronic illnesses. Such training shall address symp-
15 toms, advance care planning, and quality improvement for
16 those with fatal chronic illnesses.

17 “(d) ANNUAL REPORT.—The Secretary shall prepare
18 an annual report on care for veterans with fatal chronic
19 illnesses and the activities of the Secretary under this sec-
20 tion. The Secretary shall furnish such report to the Sec-
21 retary of Health and Human Services each year in suffi-
22 cient time for inclusion in the annual report of that Sec-
23 retary under section 4(j) of the Living Well with Fatal
24 Chronic Illness Act of 2002.

1 “(e) COOPERATION WITH COMMUNITY SERVICE PRO-
2 VIDERS.—(1) In carrying out this section, the Secretary
3 shall, to the extent practicable, take appropriate steps,
4 through collaborative agreements or otherwise, to cooper-
5 ate with community service providers that provide home
6 and hospice care.

7 “(2) Such steps shall, to the extent practicable,
8 include—

9 “(A) developing documentation of advance care
10 plans for persons with fatal chronic illnesses that are
11 acceptable to all providers of care for those persons;

12 “(B) developing service programs for persons
13 with fatal chronic illnesses under which Department
14 facilities or personnel may be used for part of the
15 array of services provided to such persons; and

16 “(C) developing protocols that facilitate the
17 placement with community service providers sup-
18 ported by the medicare or medicaid programs of vet-
19 erans with fatal chronic illnesses when such a place-
20 ment would be more efficient or effective for the
21 timely provision of services for the community in
22 which the facilities are located and for such veterans
23 than the provision of those services directly through
24 Department facilities.

1 “(3) When the Secretary, as part of service programs
 2 authorized by this subsection, provides services to a person
 3 with a fatal chronic illness who is not a veteran, the Sec-
 4 retary shall, as a condition of providing such services, be
 5 reimbursed by appropriate community service providers
 6 for the costs of such services.

7 “(f) SUPPORT FOR VOLUNTEER AND COMMUNITY
 8 SUPPORT OF VETERANS LIVING AT HOME.—The Sec-
 9 retary shall make grants to support volunteer and commu-
 10 nity support of veterans living at home who have fatal
 11 chronic illnesses. The Secretary may establish the min-
 12 imum number of volunteers an entity must have in order
 13 to be eligible for a grant under this subsection.

14 “(g) DEFINITION.—For purposes of this section, the
 15 term ‘fatal chronic illness’ means a disease (or diseases),
 16 condition (or conditions), or disorder (or disorders) that
 17 ordinarily worsens and causes death and that causes a
 18 physical or mental disability or periodic episodes of signifi-
 19 cant loss of functional capacity.”.

20 (2) The table of sections at the beginning of such
 21 chapter is amended by inserting after the item relating
 22 to section 7323 the following new item:

“7324. Programs for patients with fatal chronic illnesses.”.

23 (b) AUTHORIZATION OF APPROPRIATIONS.—There
 24 are authorized to be appropriated to the Secretary of Vet-
 25 erans Affairs to carry out section 7324 of title 38, United

- 1 States Code, as added by subsection (a), the amount of
- 2 \$5,000,000 for each of fiscal years 2003 through 2007.

