

108TH CONGRESS
1ST SESSION

H. R. 3127

To improve the palliative and end-of-life care provided to children with life-threatening conditions, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 17, 2003

Ms. PRYCE of Ohio (for herself and Mr. MURTHA) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Ways and Means, 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 improve the palliative and end-of-life care provided to children with life-threatening conditions, 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; TABLE OF CONTENTS.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Pediatric Palliative Care Act of 2003”.

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

Sec. 1. Short title; table of contents.

TITLE I—GRANTS TO EXPAND PEDIATRIC PALLIATIVE CARE
SERVICES AND RESEARCH

- Sec. 101. Education and training.
 Sec. 102. Grants to expand pediatric palliative care.
 Sec. 103. Health professions fellowships and residency grants.
 Sec. 104. Model program grants.
 Sec. 105. Research.

TITLE II—PEDIATRIC PALLIATIVE CARE DEMONSTRATION
PROJECTS

- Sec. 201. Medicare pediatric palliative care demonstration projects.
 Sec. 202. Private sector pediatric palliative care demonstration projects.
 Sec. 203. Authorization of appropriations.

1 **TITLE I—GRANTS TO EXPAND**
 2 **PEDIATRIC PALLIATIVE CARE**
 3 **SERVICES AND RESEARCH**

4 **SEC. 101. EDUCATION AND TRAINING.**

5 Subpart 2 of part E of title VII of the Public Health
 6 Service Act (42 U.S.C. 295 et seq.) is amended—

7 (1) in section 770(a) by inserting “except for
 8 section 771,” after “carrying out this subpart”; and

9 (2) by adding at the end the following:

10 **“SEC. 771. PEDIATRIC PALLIATIVE CARE SERVICES EDU-**
 11 **CATION AND TRAINING.**

12 “(a) ESTABLISHMENT.—The Secretary may award
 13 grants to eligible entities to provide training in pediatric
 14 palliative care and related services.

15 “(b) ELIGIBLE ENTITY DEFINED.—

16 “(1) IN GENERAL.—In this section the term ‘el-
 17 ible entity’ means a health care provider that is af-
 18 filiated with an academic institution, that is pro-
 19 viding comprehensive pediatric palliative care serv-

1 ices, alone or through an arrangement with another
2 entity, and that has demonstrated experience in pro-
3 viding training and consultative services in pediatric
4 palliative care including—

5 “(A) children’s hospitals or other hospitals
6 or medical centers with significant capacity in
7 caring for children with life-threatening condi-
8 tions;

9 “(B) pediatric hospices or hospices with
10 significant pediatric palliative care programs;

11 “(C) home health agencies with a dem-
12 onstrated capacity to serve children with life-
13 threatening conditions and that provide pedi-
14 atric palliative care; and

15 “(D) any other entity that the Secretary
16 determines is appropriate.

17 “(2) LIFE-THREATENING CONDITION DE-
18 FINED.—In this subsection, the term ‘life-threat-
19 ening condition’ has the meaning given such term by
20 the Secretary (in consultation with hospice programs
21 (as defined in section 1861(dd)(2) of the Social Se-
22 curity Act (42 U.S.C. 1395x(dd)(2))) and academic
23 experts in end-of-life care), except that the Secretary
24 may not limit such term to individuals who are ter-

1 minally ill (as defined in section 1861(dd)(3) of the
2 Social Security Act (42 U.S.C. 1395x(dd)(3))).

3 “(c) AUTHORIZED ACTIVITIES.—Grant funds award-
4 ed under subsection (a) shall be used to—

5 “(1) provide short-term training and education
6 programs in pediatric palliative care for the range of
7 interdisciplinary health professionals and others pro-
8 viding such care;

9 “(2) provide consultative services and guidance
10 to health care providers that are developing and
11 building comprehensive pediatric palliative care pro-
12 grams;

13 “(3) develop regional information outreach and
14 other resources to assist clinicians and families in
15 local and outlying communities and rural areas;

16 “(4) develop or evaluate current curricula and
17 educational materials being used in providing such
18 education and guidance relating to pediatric pallia-
19 tive care;

20 “(5) facilitate the development, assessment, and
21 implementation of clinical practice guidelines and in-
22 stitutional protocols and procedures for pediatric
23 palliative, end-of-life, and bereavement care; and

1 “(2) hospices with a demonstrated capacity and
2 ability to care for children with life-threatening con-
3 ditions and their families; and

4 “(3) home health agencies with—

5 “(A) a demonstrated capacity and ability
6 to care for children with life-threatening condi-
7 tions; and

8 “(B) expertise in providing palliative care.

9 “(c) AUTHORIZED ACTIVITIES.—Grant funds award-
10 ed under subsection (a) shall be used to—

11 “(1) create new pediatric palliative care pro-
12 grams;

13 “(2) start or expand needed additional care set-
14 tings, such as respite, hospice, inpatient day serv-
15 ices, or other care settings to provide a continuum
16 of care across inpatient, home, and community-based
17 settings;

18 “(3) expand comprehensive pediatric palliative
19 care services, including care coordination services, to
20 greater numbers of children and broader service
21 areas, including regional and rural outreach; and

22 “(4) support communication linkages and care
23 coordination, telemedicine and teleconferencing, and
24 measures to improve patient safety.

1 “(1) a pediatric department of a medical school
2 and other related departments including—

3 “(A) oncology;

4 “(B) virology;

5 “(C) neurology; and

6 “(D) psychiatry;

7 “(2) a school of nursing;

8 “(3) a school of psychology and social work;

9 and

10 “(4) a children’s hospital or other hospital with
11 a significant number of pediatric patients with life-
12 threatening conditions.

13 “(c) APPLICATION.—Each eligible entity desiring a
14 grant under this section shall submit an application to the
15 Director at such time, in such manner, and containing
16 such information as the Director may require.

17 “(d) AUTHORIZATION OF APPROPRIATIONS.—There
18 are authorized to be appropriated to carry out this section
19 \$5,000,000 for each of fiscal years 2004 through 2008.”.

20 **SEC. 104. MODEL PROGRAM GRANTS.**

21 Part Q of title III of the Public Health Service Act
22 (42 U.S.C. 280h et seq.), as amended by section 102, is
23 further amended by adding at the end the following:

1 **“SEC. 399Z-2. MODEL PROGRAM GRANTS.**

2 “(a) ESTABLISHMENT.—The Secretary may award
3 grants to eligible entities to enhance pediatric palliative
4 care and care for children with life-threatening conditions
5 in general pediatric or family practice residency training
6 programs through the development of model programs.

7 “(b) ELIGIBLE ENTITY DEFINED.—In this section
8 the term ‘eligible entity’ means a pediatric department
9 of—

10 “(1) a medical school;

11 “(2) a children’s hospital; or

12 “(3) any other hospital with a general pediatric
13 or family practice residency program that serves a
14 significant number of pediatric patients with life-
15 threatening conditions.

16 “(c) APPLICATION.—Each eligible entity desiring a
17 grant under this section shall submit an application to the
18 Administrator at such time, in such manner, and con-
19 taining such information as the Administrator may re-
20 quire.

21 “(d) AUTHORIZATION OF APPROPRIATIONS.—There
22 are authorized to be appropriated to carry out this section
23 \$5,000,000 for each of fiscal years 2004 through 2008.”.

24 **SEC. 105. RESEARCH.**

25 (a) PAIN AND SYMPTOM MANAGEMENT.—The Direc-
26 tor of the National Institutes of Health (in this section

1 referred to as the “Director”) shall provide translational
2 research grants to fund research in pediatric pain and
3 symptom management that will utilize existing facilities
4 of the National Institutes of Health including—

- 5 (1) pediatric pharmacological research units;
- 6 (2) the general clinical research centers; and
- 7 (3) other centers providing infrastructure for
8 patient oriented research.

9 (b) ELIGIBLE ENTITIES.—In carrying out subsection
10 (a), the Director may award grants for the conduct of re-
11 search to—

- 12 (1) children’s hospitals or other hospitals serv-
13 ing a significant number of children with life-threat-
14 ening conditions;
- 15 (2) pediatric departments of medical schools;
- 16 (3) institutions currently participating in Na-
17 tional Institutes of Health network of pediatric
18 pharmacological research units; and
- 19 (4) hospices with pediatric palliative care pro-
20 grams and academic affiliations.

21 (c) AUTHORIZATION OF APPROPRIATIONS.—There
22 are authorized to be appropriated to carry out this section
23 \$10,000,000, to remain available until expended.

1 **TITLE II—PEDIATRIC PALLIA-**
2 **TIVE CARE DEMONSTRATION**
3 **PROJECTS**

4 **SEC. 201. MEDICARE PEDIATRIC PALLIATIVE CARE DEM-**
5 **ONSTRATION PROJECTS.**

6 (a) DEFINITIONS.—In this section:

7 (1) CARE COORDINATION SERVICES.—The term
8 “care coordination services” means services that pro-
9 vide for the coordination of, and assistance with, re-
10 ferral for medical and other services, including mul-
11 tidisciplinary care conferences, coordination with
12 other providers involved in care of the eligible child,
13 patient and family caregiver education and coun-
14 seling, and such other services as the Secretary de-
15 termines to be appropriate in order to facilitate the
16 coordination and continuity of care furnished to an
17 individual.

18 (2) DEMONSTRATION PROJECT.—The term
19 “demonstration project” means a demonstration
20 project established by the Secretary under sub-
21 section (b)(1).

22 (3) ELIGIBLE CHILD.—The term “eligible
23 child” means an individual with a life-threatening
24 condition who is entitled to benefits under part A of

1 the medicare program and who is under 18 years of
2 age.

3 (4) ELIGIBLE PROVIDER.—The term “eligible
4 provider” means—

5 (A) a pediatric palliative care program that
6 is a public agency or private organization (or a
7 subdivision thereof) which—

8 (i)(I) is primarily engaged in pro-
9 viding the care and services described in
10 section 1861(dd)(1) of the Social Security
11 Act (42 U.S.C. 1395(dd)(1)) and makes
12 such services available (as needed) on a
13 24-hour basis and which also provides
14 counseling (including bereavement coun-
15 seling) for the immediate family of eligible
16 children;

17 (II) provides for such care and serv-
18 ices in eligible children’s homes, on an out-
19 patient basis, and on a short-term inpa-
20 tient basis, directly or under arrangements
21 made by the agency or organization, except
22 that—

23 (aa) the agency or organization
24 must routinely provide directly sub-
25 stantially all of each of the services

1 described in subparagraphs (A), (C),
2 and (H) of such section 1861(dd)(1);
3 (bb) in the case of other services
4 described in such section 1861(dd)(1)
5 which are not provided directly by the
6 agency or organization, the agency or
7 organization must maintain profes-
8 sional management responsibility for
9 all such services furnished to an eligi-
10 ble child, regardless of the location or
11 facility in which such services are fur-
12 nished; and
13 (III)(aa) identifies medical, commu-
14 nity, and social service needs;
15 (bb) simplifies access to service;
16 (cc) uses the full range of community
17 resources, including the friends and family
18 of the eligible child; and
19 (dd) provides educational opportuni-
20 ties relating to health care; and
21 (ii) has an interdisciplinary group of
22 personnel which—
23 (I) includes at least—
24 (aa) 1 physician (as defined
25 in section 1861(r)(1) of the So-

1 cial Security Act (42 U.S.C.
2 1395x(r)(1));

3 (bb) 1 registered profes-
4 sional nurse; and

5 (cc) 1 social worker;
6 employed by or, in the case of a physi-
7 cian described in item (aa), under
8 contract with the agency or organiza-
9 tion, and also includes at least 1 pas-
10 toral or other counselor;

11 (II) provides (or supervises the
12 provision of) the care and services de-
13 scribed in such section 1861(dd)(1);
14 and

15 (III) establishes the policies gov-
16 erning the provision of such care and
17 services;

18 (iii) maintains central clinical records
19 on all patients;

20 (iv) does not discontinue the palliative
21 care it provides with respect to an eligible
22 child because of the inability of the eligible
23 child to pay for such care;

24 (v)(I) uses volunteers in its provision
25 of care and services in accordance with

1 standards set by the Secretary, which
2 standards shall ensure a continuing level of
3 effort to use such volunteers; and

4 (II) maintains records on the use of
5 these volunteers and the cost savings and
6 expansion of care and services achieved
7 through the use of these volunteers;

8 (vi) in the case of an agency or orga-
9 nization in any State in which State or ap-
10 plicable local law provides for the licensing
11 of agencies or organizations of this nature,
12 is licensed pursuant to such law;

13 (vii) seeks to ensure that children and
14 families receive complete, timely, under-
15 standable information about diagnosis,
16 prognosis, treatments, and palliative care
17 options;

18 (viii) ensures that children and fami-
19 lies participate in effective and timely pre-
20 vention, assessment, and treatment of
21 physical and psychological symptoms of
22 distress; and

23 (ix) meets such other requirements as
24 the Secretary may find necessary in the in-
25 terest of the health and safety of the eligi-

1 ble children who are provided with pallia-
2 tive care by such agency or organization;
3 and

4 (B) any other individual or entity with an
5 agreement under section 1866 of the Social Se-
6 curity Act (42 U.S.C. 1395cc) that—

7 (i) has demonstrated experience in
8 providing interdisciplinary team-based pal-
9 liative care and care coordination services
10 (as defined in paragraph (1)) to pediatric
11 populations; and

12 (ii) the Secretary determines is appro-
13 priate.

14 (5) LIFE-THREATENING CONDITION.—The term
15 “life-threatening condition” has the meaning given
16 such term by the Secretary (in consultation with
17 hospice programs (as defined in section 1861(dd)(2)
18 of the Social Security Act (42 U.S.C. 1395x(dd)(2)))
19 and academic experts in end-of-life care), except that
20 the Secretary may not limit such term to individuals
21 who are terminally ill (as defined in section
22 1861(dd)(3) of the Social Security Act (42 U.S.C.
23 1395x(dd)(3))).

24 (6) MEDICARE PROGRAM.—The term “medicare
25 program” means the health benefits program under

1 title XVIII of the Social Security Act (42 U.S.C.
2 1395 et seq.).

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

5 (b) PEDIATRIC PALLIATIVE CARE DEMONSTRATION
6 PROJECTS.—

7 (1) ESTABLISHMENT.—The Secretary shall es-
8 tablish demonstration projects in accordance with
9 the provisions of this subsection to provide pediatric
10 palliative care to eligible children.

11 (2) PARTICIPATION.—

12 (A) ELIGIBLE PROVIDERS.—Any eligible
13 provider may furnish items or services covered
14 under the pediatric palliative care benefit.

15 (B) ELIGIBLE CHILDREN.—The Secretary
16 shall permit any eligible child residing in the
17 service area of an eligible provider participating
18 in a demonstration project to participate in
19 such project on a voluntary basis.

20 (c) SERVICES UNDER DEMONSTRATION
21 PROJECTS.—

22 (1) IN GENERAL.—Except as otherwise pro-
23 vided in this subsection, the provisions of section
24 1814(i) of the Social Security Act (42 U.S.C.
25 1395f(i)) shall apply to the payment for pediatric

1 palliative care provided under the demonstration
2 projects in the same manner in which such section
3 applies to the payment for hospice care (as defined
4 in section 1861(dd)(1) of the Social Security Act (42
5 U.S.C. 1395x(dd)(1))) provided under the medicare
6 program.

7 (2) COVERAGE OF PEDIATRIC PALLIATIVE
8 CARE.—

9 (A) IN GENERAL.—Notwithstanding sec-
10 tion 1862(a)(1)(C) of the Social Security Act
11 (42 U.S.C. 1395y(a)(1)(C)), the Secretary shall
12 provide for reimbursement for items and serv-
13 ices provided under the pediatric palliative care
14 benefit made available under the demonstration
15 projects in a manner that is consistent with the
16 requirements of subparagraph (B).

17 (B) BENEFIT.—Under the pediatric pallia-
18 tive care benefit, the following requirements
19 shall apply:

20 (i) WAIVER OF REQUIREMENT TO
21 ELECT HOSPICE CARE.—Each eligible child
22 may receive benefits without an election
23 under section 1812(d)(1) of the Social Se-
24 curity Act (42 U.S.C. 1395d(d)(1)) to re-
25 ceive hospice care (as defined in section

1 1861(dd)(1) of such Act (42 U.S.C.
2 1395x(dd)(1))) having been made with re-
3 spect to the eligible child.

4 (ii) AUTHORIZATION FOR CURATIVE
5 TREATMENT.—Each eligible child may con-
6 tinue to receive benefits for disease and
7 symptom modifying treatment under the
8 medicare program.

9 (iii) PROVISION OF CARE COORDINA-
10 TION SERVICES.—Each eligible child shall
11 receive care coordination services (as de-
12 fined in subsection (a)(1)) and hospice
13 care (as so defined) through an eligible
14 provider participating in a demonstration
15 project, regardless of whether such indi-
16 vidual has been determined to be termi-
17 nally ill (as defined in section 1861(dd)(3)
18 of the Social Security Act (42 U.S.C.
19 1395x(dd)(3))).

20 (iv) AVAILABILITY OF INFORMATION
21 ON PEDIATRIC PALLIATIVE CARE.—Each
22 eligible child and the family of such child
23 shall receive information and education in
24 order to better understand the utility of
25 pediatric palliative care.

1 (v) AVAILABILITY OF BEREAVEMENT
2 COUNSELING.—Each family of an eligible
3 child shall receive bereavement counseling,
4 if appropriate.

5 (vi) ADDITIONAL BENEFITS.—Under
6 the demonstration projects, the Secretary
7 may include any other item or service—

8 (I) for which payment may other-
9 wise be made under the medicare pro-
10 gram; and

11 (II) that is consistent with the
12 recommendations contained in the re-
13 port published in 2003 by the Insti-
14 tute of Medicine of the National
15 Academy of Sciences entitled “When
16 Children Die: Improving Palliative
17 and End-of-Life Care for Children
18 and Their Families”.

19 (C) PAYMENT.—

20 (i) ESTABLISHMENT OF PAYMENT
21 METHODOLOGY.—The Secretary shall es-
22 tablish a methodology for determining the
23 amount of payment for pediatric palliative
24 care furnished under the demonstration
25 projects that is similar to the methodology

1 for determining the amount of payment for
2 hospice care (as defined in section
3 1861(dd)(1) of the Social Security Act (42
4 U.S.C. 1395x(dd)(1))) under section
5 1814(i) of such Act (42 U.S.C. 1395f(i)),
6 except as provided in the following sub-
7 clauses:

8 (I) AMOUNT OF PAYMENT.—Sub-
9 ject to subclauses (II) and (III), the
10 amount of payment for pediatric pal-
11 liative care shall be equal to the
12 amount that would be paid for hospice
13 care (as so defined), increased by an
14 appropriate percentage to account for
15 the additional costs of providing be-
16 reavement counseling and care coordi-
17 nation services (as defined in sub-
18 section (a)(1)).

19 (II) WAIVER OF HOSPICE CAP.—
20 The limitation under section
21 1814(i)(2) of the Social Security Act
22 (42 U.S.C. 1395f(i)(2)) shall not
23 apply with respect to pediatric pallia-
24 tive care and amounts paid for pedi-
25 atric palliative care under this sub-

1 paragraph shall not be counted
2 against the cap amount described in
3 such section.

4 (III) SEPARATE PAYMENT FOR
5 COUNSELING SERVICES.—Notwith-
6 standing section 1814(i)(1)(A) of the
7 Social Security Act (42 U.S.C.
8 1395f(i)(1)(A)), the Secretary may
9 pay for bereavement counseling as a
10 separate service.

11 (ii) SPECIAL RULES FOR PAYMENT OF
12 MEDICARE+CHOICE ORGANIZATIONS.—The
13 Secretary shall establish procedures under
14 which the Secretary provides for an appro-
15 priate adjustment in the monthly payments
16 made under section 1853 of the Social Se-
17 curity Act (42 U.S.C. 1395w–23) to any
18 Medicare+Choice organization that pro-
19 vides health care items or services to an el-
20 igible child who is participating in a dem-
21 onstration project.

22 (3) COVERAGE OF PEDIATRIC PALLIATIVE CARE
23 CONSULTATION SERVICES.—Under the demonstra-
24 tion projects, the Secretary shall provide for a one-
25 time payment on behalf of each eligible child who

1 has not yet elected to participate in the demonstra-
2 tion project for services that are furnished by a phy-
3 sician who is either the medical director or an em-
4 ployee of an eligible provider participating in such
5 a project and that consist of—

6 (A) an evaluation of the individual’s need
7 for pain and symptom management, including
8 the need for pediatric palliative care;

9 (B) counseling the individual and the fam-
10 ily of such individual with respect to the bene-
11 fits of pediatric palliative care and care options;
12 and

13 (C) if appropriate, advising the individual
14 and the family of such individual regarding ad-
15 vanced care planning.

16 (d) CONDUCT OF DEMONSTRATION PROJECTS.—

17 (1) SITES.—The Secretary shall conduct dem-
18 onstration projects in at least 4, but not more than
19 8, sites.

20 (2) SELECTION OF SITES.—The Secretary shall
21 select demonstration sites on the basis of proposals
22 submitted under paragraph (3) that are located in
23 geographic areas that—

24 (A) include both urban and rural eligible
25 providers; and

1 (B) are geographically diverse and readily
2 accessible to a significant number of eligible
3 children.

4 (3) PROPOSALS.—The Secretary shall accept
5 proposals to furnish pediatric palliative care under
6 the demonstration projects from any eligible provider
7 at such time, in such manner, and in such form as
8 the Secretary may reasonably require.

9 (4) FACILITATION OF EVALUATION.—The Sec-
10 retary shall design the demonstration projects to fa-
11 cilitate the evaluation conducted under subsection
12 (e)(1).

13 (5) DURATION.—The Secretary shall complete
14 the demonstration projects within a period of 5
15 years that includes a period of 1 year during which
16 the Secretary shall complete the evaluation under
17 subsection (e)(1).

18 (e) EVALUATION AND REPORTS TO CONGRESS.—

19 (1) EVALUATION.—During the 1-year period
20 following the first 4 years of the demonstration
21 projects, the Secretary shall complete an evaluation
22 of the demonstration projects in order—

23 (A) to determine the short-term and long-
24 term costs and benefits of changing—

1 (i) hospice care (as defined in section
2 1861(dd)(1) of the Social Security Act (42
3 U.S.C. 1395x(dd)(1))) provided under the
4 medicare program to children to include
5 the pediatric palliative care furnished
6 under the demonstration projects; and

7 (ii) the medicare program to permit
8 eligible children to receive curative and pal-
9 liative care simultaneously;

10 (B) to review the implementation of the
11 demonstration projects compared to rec-
12 ommendations contained in the report published
13 in 2003 by the Institute of Medicine of the Na-
14 tional Academy of Sciences entitled “When
15 Children Die: Improving Palliative and End-of-
16 Life Care for Children and Their Families”;

17 (C) to determine the quality and duration
18 of palliative care for individuals who receive
19 such care under the demonstration projects who
20 would not be eligible to receive such care under
21 the medicare program;

22 (D) whether any increase in payments for
23 pediatric palliative care is offset by savings in
24 other parts of the medicare program; and

1 (E) the projected cost of implementing the
2 demonstration projects on a national basis.

3 (2) REPORTS.—

4 (A) INTERIM REPORT.—Not later than the
5 date that is 2 years after the date on which the
6 demonstration projects are implemented, the
7 Secretary shall submit an interim report to
8 Congress on the demonstration projects.

9 (B) FINAL REPORT.—Not later than the
10 date that is 1 year after the date on which the
11 demonstration projects end, the Secretary shall
12 submit a final report to Congress on the dem-
13 onstration projects that includes the results of
14 the evaluation conducted under paragraph (1)
15 together with such recommendations for legisla-
16 tion or administrative action as the Secretary
17 determines is appropriate.

18 (f) WAIVER OF MEDICARE REQUIREMENTS.—The
19 Secretary shall waive compliance with such requirements
20 of the medicare program to the extent and for the period
21 the Secretary finds necessary to conduct the demonstra-
22 tion projects.

23 **SEC. 202. PRIVATE SECTOR PEDIATRIC PALLIATIVE CARE**
24 **DEMONSTRATION PROJECTS.**

25 (a) DEFINITIONS.—In this section:

1 (1) DEMONSTRATION PROJECT.—The term
2 “demonstration project” means a demonstration
3 project established by the Secretary under sub-
4 section (b)(1).

5 (2) ELIGIBLE CHILD.—The term “eligible
6 child” means an individual with a life-threatening
7 condition who is—

8 (A) under 18 years of age;

9 (B) enrolled for health benefits coverage
10 under an eligible health plan; and

11 (C) not enrolled under (or entitled to) ben-
12 efits under a health plan described in para-
13 graph (3)(C).

14 (3) ELIGIBLE HEALTH PLAN.—

15 (A) IN GENERAL.—Subject to clauses (ii)
16 and (iii), the term “eligible health plan” means
17 an individual or group plan that provides, or
18 pays the cost of, medical care (as such term is
19 defined in section 2791 of the Public Health
20 Service Act (42 U.S.C. 300gg–91)).

21 (B) TYPES OF PLANS INCLUDED.—For
22 purposes of subparagraph (A), the term “eligi-
23 ble health plan” includes the following health
24 plans, and any combination thereof:

1 (i) A group health plan (as defined in
2 section 2791(a) of the Public Health Serv-
3 ice Act (42 U.S.C. 300gg-91(a))), but only
4 if the plan—

5 (I) has 50 or more participants
6 (as defined in section 3(7) of the Em-
7 ployee Retirement Income Security
8 Act of 1974 (29 U.S.C. 1002(7))); or

9 (II) is administered by an entity
10 other than the employer who estab-
11 lished and maintains the plan.

12 (ii) A health insurance issuer (as de-
13 fined in section 2791(b) of the Public
14 Health Service Act (42 U.S.C. 300gg-
15 91(b))).

16 (iii) A health maintenance organiza-
17 tion (as defined in section 2791(b) of the
18 Public Health Service Act (42 U.S.C.
19 300gg-91(b))).

20 (iv) A long-term care policy, including
21 a nursing home fixed indemnity policy (un-
22 less the Secretary determines that such a
23 policy does not provide sufficiently com-
24 prehensive coverage of a benefit so that the
25 policy should be treated as a health plan).

1 (v) An employee welfare benefit plan
2 or any other arrangement which is estab-
3 lished or maintained for the purpose of of-
4 fering or providing health benefits to the
5 employees of 2 or more employers.

6 (vi) Health benefits coverage provided
7 under a contract under the Federal em-
8 ployees health benefits program under
9 chapter 89 of title 5, United States Code.

10 (C) TYPES OF PLANS EXCLUDED.—For
11 purposes of subparagraph (A), the term “eligi-
12 ble health plan” does not include any of the fol-
13 lowing health plans:

14 (i) The medicare program under title
15 XVIII of the Social Security Act (42
16 U.S.C. 1395 et seq.).

17 (ii) The medicaid program under title
18 XIX of the Social Security Act (42 U.S.C.
19 1396 et seq.).

20 (iii) A medicare supplemental policy
21 (as defined in section 1882(g)(1) of the
22 Social Security Act (42 U.S.C. 1395ss et
23 seq.).

1 (iv) The health care program for ac-
2 tive military personnel under title 10,
3 United States Code.

4 (v) The veterans health care program
5 under chapter 17 of title 38, United States
6 Code.

7 (vi) The Civilian Health and Medical
8 Program of the Uniformed Services
9 (CHAMPUS), as defined in section
10 1072(4) of title 10, United States Code.

11 (vii) The Indian health service pro-
12 gram under the Indian Health Care Im-
13 provement Act (25 U.S.C. 1601 et seq.).

14 (4) ELIGIBLE ORGANIZATION.—The term “eligi-
15 ble organization” means an organization that pro-
16 vides health benefits coverage under an eligible
17 health plan.

18 (5) LIFE-THREATENING CONDITION.—The term
19 “life-threatening condition” has the meaning given
20 such term under section 201(a)(4).

21 (6) PEDIATRIC PALLIATIVE CARE.—The term
22 “pediatric palliative care” means services of the type
23 to be furnished under the demonstration projects
24 under section 201, including care coordination serv-
25 ices (as defined in subsection (a)(1) of such section).

1 (7) PEDIATRIC PALLIATIVE CARE CONSULTA-
2 TION SERVICES.—The term “pediatric palliative care
3 consultation services” means services of the type de-
4 scribed in section 201(c)(3).

5 (8) SECRETARY.—The term “Secretary” means
6 the Secretary of Health and Human Services, acting
7 through the Director of the Agency for Healthcare
8 Research and Quality.

9 (b) NONMEDICARE PEDIATRIC PALLIATIVE CARE
10 DEMONSTRATION PROJECTS.—

11 (1) ESTABLISHMENT.—The Secretary shall es-
12 tablish demonstration projects under this section at
13 the same time as the Secretary establishes the dem-
14 onstration projects under section 201 and in accord-
15 ance with the provisions of this subsection to dem-
16 onstrate the provision of pediatric palliative care and
17 pediatric palliative care consultation services to eligi-
18 ble children who are not entitled to (or enrolled for)
19 coverage under the health plans described in sub-
20 section (a)(3)(C).

21 (2) PARTICIPATION.—

22 (A) ELIGIBLE ORGANIZATIONS.—The Sec-
23 retary shall permit any eligible organization to
24 participate in a demonstration project on a vol-
25 untary basis.

1 (B) ELIGIBLE CHILDREN.—Any eligible or-
2 organization participating in a demonstration
3 project shall permit any eligible child enrolled in
4 an eligible health plan offered by the organiza-
5 tion to participate in such project on a vol-
6 untary basis.

7 (c) SERVICES UNDER DEMONSTRATION
8 PROJECTS.—

9 (1) PROVISION OF PEDIATRIC PALLIATIVE CARE
10 AND CONSULTATION SERVICES.—Under a dem-
11 onstration project, each eligible organization electing
12 to participate in the demonstration project shall pro-
13 vide pediatric palliative care and pediatric palliative
14 care consultation services to each eligible child who
15 is enrolled with the organization and who elects to
16 participate in the demonstration project.

17 (2) AVAILABILITY OF ADMINISTRATIVE
18 GRANTS.—

19 (A) IN GENERAL.—Subject to subpara-
20 graph (B), the Secretary shall award grants to
21 eligible organizations electing to participate in a
22 demonstration project for the administrative
23 costs incurred by the eligible organization in
24 participating in the demonstration project, in-
25 cluding the costs of collecting and submitting

1 the data required to be submitted under sub-
2 section (d)(4)(B).

3 (B) NO PAYMENT FOR SERVICES.—The
4 Secretary may not pay eligible organizations for
5 pediatric palliative care or pediatric palliative
6 care consultation services furnished under the
7 demonstration projects.

8 (d) CONDUCT OF DEMONSTRATION PROJECTS.—

9 (1) SITES.—The Secretary shall conduct dem-
10 onstration projects in at least 4, but not more than
11 8, sites.

12 (2) SELECTION OF SITES.—The Secretary shall
13 select demonstration sites on the basis of proposals
14 submitted under paragraph (3) that are located in
15 geographic areas that—

16 (A) include both urban and rural eligible
17 organizations; and

18 (B) are geographically diverse and readily
19 accessible to a significant number of eligible
20 children.

21 (3) PROPOSALS.—

22 (A) IN GENERAL.—The Secretary shall ac-
23 cept proposals to furnish pediatric palliative
24 care and pediatric palliative care consultation
25 services under the demonstration projects from

1 any eligible organization at such time, in such
2 manner, and in such form as the Secretary may
3 require.

4 (B) APPLICATION FOR ADMINISTRATIVE
5 GRANTS.—If the eligible organization desires to
6 receive an administrative grant under sub-
7 section (e)(2), the proposal submitted under
8 subparagraph (A) shall include a request for
9 the grant, specify the amount requested, and
10 identify the purposes for which the organization
11 will use any funds made available under the
12 grant.

13 (4) COLLECTION AND SUBMISSION OF DATA.—

14 (A) COLLECTION.—Each eligible organiza-
15 tion participating in a demonstration project
16 shall collect such data as the Secretary may re-
17 quire to facilitate the evaluation to be com-
18 pleted under subsection (e)(1).

19 (B) SUBMISSION.—Each eligible organiza-
20 tion shall submit the data collected under sub-
21 paragraph (A) to the Secretary at such time, in
22 such manner, and in such form as the Secretary
23 may require.

24 (5) DURATION.—The Secretary shall complete
25 the demonstration projects within a period of 5

1 years that includes a period of 1 year during which
2 the Secretary shall complete the evaluation under
3 subsection (e)(1).

4 (e) EVALUATION AND REPORTS TO CONGRESS AND
5 ELIGIBLE ORGANIZATIONS.—

6 (1) EVALUATION.—During the 1-year period
7 following the first 4 years of the demonstration
8 projects, the Secretary shall complete an evaluation
9 of the demonstration projects.

10 (2) REPORTS.—

11 (A) INTERIM REPORT.—Not later than the
12 date that is 2 years after the date on which the
13 demonstration projects are implemented, the
14 Secretary shall submit an interim report to
15 Congress and each eligible organization partici-
16 pating in a demonstration project on the dem-
17 onstration projects.

18 (B) FINAL REPORT.—Not later than the
19 date that is 1 year after the date on which the
20 demonstration projects end, the Secretary shall
21 submit a final report to Congress and each eli-
22 gible organization participating in a demonstra-
23 tion project on the demonstration projects that
24 includes the results of the evaluation conducted
25 under paragraph (1) together with such rec-

1 ommendations for legislation or administrative
2 action as the Secretary determines is appro-
3 priate.

4 **SEC. 203. AUTHORIZATION OF APPROPRIATIONS.**

5 (a) **IN GENERAL.**—There are authorized to be appro-
6 priated—

7 (1) \$2,500,000, to carry out the demonstration
8 projects under section 201; and

9 (2) \$2,500,000, to carry out the demonstration
10 projects under section 202, including for awarding
11 grants under subsection (c)(2) of such section.

12 (b) **AVAILABILITY.**—Sums appropriated under sub-
13 section (a) shall remain available, without fiscal year limi-
14 tation, until expended.

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