

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.

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## 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

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## 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:

See. 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 EDUCATION 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                   igible 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               “(6) assure that families of children with life-  
2 threatening conditions are an integral part of these  
3 processes.

4               “(d) AUTHORIZATION OF APPROPRIATIONS.—There  
5 are authorized to be appropriated to carry out this section  
6 \$5,000,000 for each of fiscal years 2004 through 2008.”.

7 **SEC. 102. GRANTS TO EXPAND PEDIATRIC PALLIATIVE  
8 CARE.**

9               Part Q of title III of the Public Health Service Act  
10 (42 U.S.C. 280h et seq.) is amended by adding at the end  
11 the following:

12 **“SEC. 399Z-1. GRANTS TO EXPAND PEDIATRIC PALLIATIVE  
13 CARE.**

14               “(a) ESTABLISHMENT.—The Secretary, acting  
15 through the Administrator of the Health Resources and  
16 Services Administration may award grants to eligible enti-  
17 ties to implement or expand pediatric palliative care pro-  
18 grams for children with life-threatening conditions.

19               “(b) ELIGIBLE ENTITY DEFINED.—In this section,  
20 the term ‘eligible entity’ means—

21               “(1) children’s hospitals or other hospitals with  
22 a capacity and ability to care for children with life-  
23 threatening conditions;

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       “(d) APPLICATION.—Each eligible entity desiring a  
2 grant under this section shall submit an application to the  
3 Administrator at such time, in such manner, and con-  
4 taining such information as the Administrator may re-  
5 quire.

6       “(e) AUTHORIZATION OF APPROPRIATIONS.—There  
7 are authorized to be appropriated to carry out this section  
8 \$10,000,000 for each of fiscal years 2004 through 2008.”.

9 SEC. 103. PEDIATRIC PALLIATIVE CARE TRAINING AND  
10 RESIDENCY GRANTS.

11       Part A of title IV of the Public Health Service Act  
12 (42 U.S.C. 281 et seq.) is amended by adding at the end  
13 the following:

14 "SEC. 404F. PEDIATRIC PALLIATIVE CARE TRAINING AND  
15 RESIDENCY GRANTS.

16        "(a) ESTABLISHMENT.—The Director of the Na-  
17 tional Institutes of Health is authorized to award training  
18 grants to eligible entities to expand the number of physi-  
19 cians, nurses, mental health professionals, and appropriate  
20 allied health professionals and specialists (as determined  
21 by the Secretary) with pediatric palliative clinical training  
22 and research experience.

23        "(b) ELIGIBLE ENTITY DEFINED.—In this section,  
24 the term 'eligible entity' means—

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

described in subparagraphs (A), (C), and (H) of such section 1861(dd)(1);

(bb) in the case of other services described in such section 1861(dd)(1) which are not provided directly by the agency or organization, the agency or organization must maintain professional management responsibility for all such services furnished to an eligible child, regardless of the location or facility in which such services are furnished; and

(III)(aa) identifies medical, community, and social service needs;

(bb) simplifies access to service;

(cc) uses the full range of community resources, including the friends and family of the eligible child; and

(dd) provides educational opportunities relating to health care; and

(ii) has an interdisciplinary group of personnel which—

(I) includes at least—

(aa) 1 physician (as defined

in section 1861(r)(1) of the So-

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 organ-  
9 ization 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-

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.

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

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

18 (e) EVALUATION AND REPORTS TO CONGRESS.—

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

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

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

3 (2) REPORTS.—

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:

8 (A) under 18 years of age;

(C) not enrolled under (or entitled to) benefits under a health plan described in paragraph (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 “eli-  
23 gible 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.

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 “eli-  
12 gible 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.).

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).

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

## 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.

7 (c) SERVICES UNDER DEMONSTRATION  
8 PROJECTS.—

17 (2) AVAILABILITY OF ADMINISTRATIVE  
18 GRANTS.—

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 (c)(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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