

110TH CONGRESS  
1ST SESSION

# H. R. 1634

To amend the Public Health Service Act to establish grant programs to provide for education and outreach on newborn screening and coordinated followup care once newborn screening has been conducted, to reauthorize programs under part A of title XI of such Act, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

MARCH 21, 2007

Ms. ROYBAL-ALLARD (for herself and Mr. SIMPSON) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To amend the Public Health Service Act to establish grant programs to provide for education and outreach on newborn screening and coordinated followup care once newborn screening has been conducted, to reauthorize programs under part A of title XI of such Act, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Newborn Screening  
5 Saves Lives Act of 2007”.

1 **SEC. 2. FINDINGS.**

2 Congress finds the following:

3 (1) Each year, approximately 4,000,000 babies  
4 are born in the United States, and all are offered  
5 some type of newborn screening by State and private  
6 laboratories to detect certain conditions that may  
7 threaten their long-term health.

8 (2) However, there is a lack of uniformity in  
9 the number of conditions for which newborns are  
10 screened through State-based programs. Although a  
11 newborn may be screened and treated for a debili-  
12 tating condition in one State, in another State the  
13 condition may go undetected and result in perma-  
14 nent disability or even death.

15 (3) In 2004, the American College of Medical  
16 Genetics (ACMG) completed a report commissioned  
17 by the Department of Health and Human Services  
18 which recommended that every baby born in the  
19 United States be screened for 29 specific disorders,  
20 which, if diagnosed early, can be successfully man-  
21 aged or treated to prevent severe and often lifelong  
22 health consequences.

23 (4) Currently only 11 States and the District of  
24 Columbia require infants to be screened for all 29 of  
25 these recommended disorders.

1           (5) The March of Dimes estimates that 1,000  
2 of the 5,000 babies born every year in the United  
3 States with one of the 29 core conditions do not re-  
4 ceive comprehensive newborn screening that includes  
5 their particular disorder. This results in catastrophic  
6 consequences for the child and the family and enor-  
7 mous costs for society.

8           (6) Continuity plays a critical role in the  
9 screening, diagnosis, referral, and treatment of these  
10 disorders. Currently there is no national contingency  
11 plan for maintaining continuity of newborn screen-  
12 ing systems during a public health emergency, such  
13 as a catastrophic natural disaster or a widespread  
14 terrorist event, that results in State or regional dis-  
15 ruption of newborn screening services.

16 **SEC. 3. AMENDMENT TO TITLE III OF THE PUBLIC HEALTH**  
17 **SERVICE ACT.**

18           Part Q of title III of the Public Health Service Act  
19 (42 U.S.C. 280h et seq.) is amended by adding at the end  
20 the following:

21 **“SEC. 399Z-1. NEWBORN SCREENING.**

22           “(a) AUTHORIZATION OF GRANT PROGRAMS.—

23           “(1) GRANTS TO ASSIST HEALTH CARE PROFES-  
24 SIONALS.—From funds appropriated under sub-  
25 section (h), the Secretary, acting through the Asso-

1        ciate Administrator of the Maternal and Child  
2        Health Bureau of the Health Resources and Services  
3        Administration (referred to in this section as the  
4        ‘Associate Administrator’) and in consultation with  
5        the Advisory Committee on Heritable Disorders in  
6        Newborns and Children (referred to in this section  
7        as the ‘Advisory Committee’), shall award grants to  
8        eligible entities to enable such entities to assist in  
9        providing health care professionals and newborn  
10       screening laboratory personnel with—

11                    “(A) education in newborn screening; and

12                    “(B) training in—

13                            “(i) relevant and new technologies in  
14                            newborn screening; and

15                            “(ii) congenital, genetic, and meta-  
16                            bolic disorders.

17                    “(2) GRANTS TO ASSIST FAMILIES.—

18                            “(A) IN GENERAL.—From funds appro-  
19                            priated under subsection (h), the Secretary, act-  
20                            ing through the Associate Administrator and in  
21                            consultation with the Advisory Committee, shall  
22                            award grants to eligible entities to enable such  
23                            entities to develop and deliver educational pro-  
24                            grams about newborn screening to parents,  
25                            families, and patient advocacy and support

1 groups. The educational materials accom-  
2 panying such educational programs shall be  
3 provided at appropriate literacy levels.

4 “(B) AWARENESS OF THE AVAILABILITY  
5 OF PROGRAMS.—To the extent practicable, the  
6 Secretary shall make relevant health care pro-  
7 viders aware of the availability of the edu-  
8 cational programs supported pursuant to sub-  
9 paragraph (A).

10 “(3) GRANTS FOR QUALITY NEWBORN SCREEN-  
11 ING FOLLOWUP.—From funds appropriated under  
12 subsection (h), the Secretary, acting through the As-  
13 sociate Administrator and in consultation with the  
14 Advisory Committee, shall award grants to eligible  
15 entities to enable such entities to establish, main-  
16 tain, and operate a system to assess and coordinate  
17 treatment relating to congenital, genetic, and meta-  
18 bolic disorders.

19 “(b) APPLICATION.—An eligible entity that desires to  
20 receive a grant under this section shall submit an applica-  
21 tion to the Secretary at such time, in such manner, and  
22 accompanied by such information as the Secretary may  
23 require.

24 “(c) SELECTION OF GRANT RECIPIENTS.—

1           “(1) IN GENERAL.—Not later than 120 days  
2 after receiving an application under subsection (b),  
3 the Secretary, after considering the approval factors  
4 under paragraph (2), shall determine whether to  
5 award the eligible entity a grant under this section.

6           “(2) APPROVAL FACTORS.—

7           “(A) REQUIREMENTS FOR APPROVAL.—An  
8 application submitted under subsection (b) may  
9 not be approved by the Secretary unless the ap-  
10 plication contains assurances that the eligible  
11 entity—

12                   “(i) will use grant funds only for the  
13 purposes specified in the approved applica-  
14 tion and in accordance with the require-  
15 ments of this section; and

16                   “(ii) will establish such fiscal control  
17 and fund accounting procedures as may be  
18 necessary to assure proper disbursement  
19 and accounting of Federal funds paid to  
20 the eligible entity under the grant.

21           “(B) EXISTING PROGRAMS.—Prior to  
22 awarding a grant under this section, the Sec-  
23 retary shall—

24                   “(i) conduct an assessment of existing  
25 educational resources and training pro-

1           grams and coordinated systems of followup  
2           care with respect to newborn screening;  
3           and

4           “(ii) take all necessary steps to mini-  
5           mize the duplication of the resources and  
6           programs described in clause (i).

7           “(d) COORDINATION.—The Secretary shall take all  
8           necessary steps to coordinate programs funded with  
9           grants received under this section.

10          “(e) USE OF GRANT FUNDS.—

11           “(1) GRANTS TO ASSIST HEALTH CARE PROFES-  
12           SIONALS.—An eligible entity that receives a grant  
13           under subsection (a)(1) may use the grant funds to  
14           work with appropriate medical schools, nursing  
15           schools, schools of public health, schools of genetic  
16           counseling, internal education programs in State  
17           agencies, nongovernmental organizations, and pro-  
18           fessional organizations and societies to develop and  
19           deliver education and training programs that in-  
20           clude—

21           “(A) continuing medical education pro-  
22           grams for health care professionals and new-  
23           born screening laboratory personnel in newborn  
24           screening;

1           “(B) education, technical assistance, and  
2 training on new discoveries in newborn screen-  
3 ing and the use of any related technology;

4           “(C) models to evaluate the prevalence of,  
5 and assess and communicate the risks of, con-  
6 genital conditions, including the prevalence and  
7 risk of some of these conditions based on family  
8 history;

9           “(D) models to communicate effectively  
10 with parents and families about—

11                 “(i) the process and benefits of new-  
12 born screening;

13                 “(ii) how to use information gathered  
14 from newborn screening;

15                 “(iii) the meaning of screening re-  
16 sults, including the possibility of false posi-  
17 tive findings;

18                 “(iv) the right of refusal of newborn  
19 screening, if applicable; and

20                 “(v) the potential need for followup  
21 care after newborns are screened;

22           “(E) information and resources on coordi-  
23 nated systems of followup care after newborns  
24 are screened;

1           “(F) information on the disorders for  
2           which States require and offer newborn screen-  
3           ing and options for newborn screening relating  
4           to conditions in addition to such disorders;

5           “(G) information on additional newborn  
6           screening that may not be required by the  
7           State, but that may be available from other  
8           sources; and

9           “(H) other items to carry out the purpose  
10          described in subsection (a)(1) as determined ap-  
11          propriate by the Secretary.

12          “(2) GRANTS TO ASSIST FAMILIES.—An eligible  
13          entity that receives a grant under subsection (a)(2)  
14          may use the grant funds to develop and deliver to  
15          parents, families, and patient advocacy and support  
16          groups, educational programs about newborn screen-  
17          ing that include information on—

18                 “(A) what newborn screening is;

19                 “(B) how newborn screening is performed;

20                 “(C) who performs newborn screening;

21                 “(D) where newborn screening is per-  
22                 formed;

23                 “(E) the disorders for which the State re-  
24                 quires newborns to be screened;

1           “(F) different options for newborn screen-  
2           ing for disorders other than those included by  
3           the State in the mandated newborn screening  
4           program;

5           “(G) the meaning of various screening re-  
6           sults, including the possibility of false positive  
7           and false negative findings;

8           “(H) the prevalence and risk of newborn  
9           disorders, including the increased risk of dis-  
10          orders that may stem from family history;

11          “(I) coordinated systems of followup care  
12          after newborns are screened; and

13          “(J) other items to carry out the purpose  
14          described in subsection (a)(2) as determined ap-  
15          propriate by the Secretary.

16          “(3) GRANTS FOR QUALITY NEWBORN SCREEN-  
17          ING FOLLOWUP.—An eligible entity that receives a  
18          grant under subsection (a)(3) shall use the grant  
19          funds to—

20                 “(A) expand on existing procedures and  
21                 systems, where appropriate and available, for  
22                 the timely reporting of newborn screening re-  
23                 sults to individuals, families, primary care phy-  
24                 sicians, and subspecialists in congenital, ge-  
25                 netic, and metabolic disorders;

1           “(B) coordinate ongoing followup treat-  
2           ment with individuals, families, primary care  
3           physicians, and subspecialists in congenital, ge-  
4           netic, and metabolic disorders after a newborn  
5           receives an indication of the presence or in-  
6           creased risk of a disorder on a screening test;

7           “(C) ensure the seamless integration of  
8           confirmatory testing, tertiary care medical serv-  
9           ices, comprehensive genetic services including  
10          genetic counseling, and information about ac-  
11          cess to developing therapies by participation in  
12          approved clinical trials involving the primary  
13          health care of the infant;

14          “(D) analyze data, if appropriate and  
15          available, collected from newborn screenings to  
16          identify populations at risk for disorders affect-  
17          ing newborns, examine and respond to health  
18          concerns, recognize and address relevant envi-  
19          ronmental, behavioral, socioeconomic, demo-  
20          graphic, and other relevant risk factors; and

21          “(E) carry out such other activities as the  
22          Secretary may determine necessary.

23          “(f) REPORTS TO CONGRESS.—

1           “(1) IN GENERAL.—Subject to paragraph (2),  
2           the Secretary shall submit to the appropriate com-  
3           mittees of Congress reports—

4                   “(A) evaluating the effectiveness and the  
5                   impact of the grants awarded under this sec-  
6                   tion—

7                           “(i) in promoting newborn screen-  
8                           ing—

9                                   “(I) education and resources for  
10                                   families; and

11                                   “(II) education, resources, and  
12                                   training for health care professionals;

13                                   “(ii) on the successful diagnosis and  
14                                   treatment of congenital, genetic, and meta-  
15                                   bolic disorders; and

16                                   “(iii) on the continued development of  
17                                   coordinated systems of followup care after  
18                                   newborns are screened;

19                   “(B) describing and evaluating the effec-  
20                   tiveness of the activities carried out with grant  
21                   funds received under this section; and

22                   “(C) that include recommendations for  
23                   Federal actions to support—

24                           “(i) education and training in new-  
25                           born screening; and

1                   “(ii) followup care after newborns are  
2                   screened.

3                   “(2) TIMING OF REPORTS.—The Secretary shall  
4                   submit—

5                   “(A) an interim report that includes the  
6                   information described in paragraph (1), not  
7                   later than 30 months after the date on which  
8                   the first grant funds are awarded under this  
9                   section; and

10                  “(B) a subsequent report that includes the  
11                  information described in paragraph (1), not  
12                  later than 60 months after the date on which  
13                  the first grant funds are awarded under this  
14                  section.

15                  “(g) DEFINITION OF ELIGIBLE ENTITY.—In this sec-  
16                  tion, the term ‘eligible entity’ means—

17                  “(1) a State or a political subdivision of a  
18                  State;

19                  “(2) a consortium of 2 or more States or polit-  
20                  ical subdivisions of States;

21                  “(3) a territory;

22                  “(4) an Indian tribe or a hospital or outpatient  
23                  health care facility of the Indian Health Service; or

1           “(5) a nongovernmental organization with ap-  
2           propriate expertise in newborn screening, as deter-  
3           mined by the Secretary.

4           “(h) NATIONAL CONTINGENCY PLAN FOR NEWBORN  
5           SCREENING.—

6           “(1) IN GENERAL.—Not later than 180 days  
7           after the date of enactment of this section, the Sec-  
8           retary, acting through the Director of the Centers  
9           for Disease Control and Prevention and in consulta-  
10          tion with the Associate Administrator, shall develop  
11          a national contingency plan for newborn screening  
12          for use in the event of a public health emergency  
13          that results in State or regional disruption of new-  
14          born screening services.

15          “(2) REQUIREMENTS.—The contingency plan  
16          developed under paragraph (1) shall include a plan  
17          for—

18                 “(A) the collection and transport of speci-  
19                 mens;

20                 “(B) the shipment of specimens to State  
21                 newborn screening laboratories;

22                 “(C) the processing of specimens;

23                 “(D) the reporting of screening results to  
24                 physicians and families;

1           “(E) the diagnostic confirmation of posi-  
2           tive screening results;

3           “(F) ensuring the availability of treatment  
4           and management resources;

5           “(G) educating families about newborn  
6           screening; and

7           “(H) carrying out other activities deter-  
8           mined appropriate by the Secretary.

9           “(i) AUTHORIZATION OF APPROPRIATIONS.—There  
10          are authorized to be appropriated to carry out this sec-  
11          tion—

12                 “(1) \$15,000,000 for fiscal year 2008; and

13                 “(2) such sums as may be necessary for each  
14          of fiscal years 2009 through 2012.”.

15         **SEC. 4. IMPROVED NEWBORN AND CHILD SCREENING FOR**  
16                         **HERITABLE DISORDERS.**

17          Section 1109 of the Public Health Service Act (42  
18          U.S.C. 300b–8) is amended—

19                 (1) in subsection (c)(2)—

20                         (A) in subparagraph (E), by striking  
21                         “and” after the semicolon;

22                         (B) by redesignating subparagraph (F) as  
23                         subparagraph (G); and

24                         (C) by inserting after subparagraph (E)  
25                         the following:

1           “(F) an assurance that the entity has  
2           adopted and implemented, is in the process of  
3           adopting and implementing, or will use grant  
4           amounts received under this section to adopt  
5           and implement the guidelines and recommenda-  
6           tions of the Advisory Committee on Heritable  
7           Disorders in Newborns and Children established  
8           under section 1111 (referred to in this section  
9           as the ‘Advisory Committee’) that are adopted  
10          by the Secretary and in effect at the time the  
11          grant is awarded or renewed under this section,  
12          which shall include the screening of each new-  
13          born for the heritable disorders recommended  
14          by the Advisory Committee and adopted by the  
15          Secretary and the reporting of results; and”;  
16          and

17          (2) in subsection (i), by striking “such sums”  
18          and all that follows through the period at the end  
19          and inserting “\$25,000,000 for fiscal year 2008 and  
20          such sums as may be necessary for each of the fiscal  
21          years 2009 through 2012.”.

1 **SEC. 5. EVALUATING THE EFFECTIVENESS OF NEWBORN-**  
2 **AND CHILD-SCREENING PROGRAMS.**

3 Section 1110 of the Public Health Service Act (42  
4 U.S.C. 300b–9) is amended by adding at the end the fol-  
5 lowing:

6 “(d) AUTHORIZATION OF APPROPRIATIONS.—There  
7 are authorized to be appropriated to carry out this section  
8 \$5,000,000 for fiscal year 2008 and such sums as may  
9 be necessary for each of the fiscal years 2009 through  
10 2012.”.

11 **SEC. 6. ADVISORY COMMITTEE ON HERITABLE DISORDERS**  
12 **IN NEWBORNS AND CHILDREN.**

13 Section 1111 of the Public Health Service Act (42  
14 U.S.C. 300b–10) is amended—

15 (1) in subsection (b)—

16 (A) by redesignating paragraph (3) as  
17 paragraph (5);

18 (B) in paragraph (2), by striking “and”  
19 after the semicolon;

20 (C) by inserting after paragraph (2) the  
21 following:

22 “(3) recommend a uniform screening panel for  
23 newborn screening programs that includes the heri-  
24 table disorders for which all newborns should be  
25 screened, including secondary conditions that may be

1 identified as a result of the laboratory methods used  
2 for screening;

3 “(4) develop a model decision-matrix for new-  
4 born screening program expansion, and periodically  
5 update the recommended uniform screening panel  
6 described in paragraph (3) based on such decision-  
7 matrix; and”;

8 (D) in paragraph (5) (as redesignated by  
9 subparagraph (A)), by striking the period at the  
10 end and inserting “, including recommenda-  
11 tions, advice, or information dealing with—

12 “(A) followup activities, including those  
13 necessary to achieve rapid diagnosis in the  
14 short term, and those that ascertain long-term  
15 case management outcomes and appropriate ac-  
16 cess to related services;

17 “(B) diagnostic and other technology used  
18 in screening;

19 “(C) the availability and reporting of test-  
20 ing for conditions for which there is no existing  
21 treatment;

22 “(D) minimum standards and related poli-  
23 cies and procedures for State newborn screen-  
24 ing programs;

1           “(E) quality assurance, oversight, and  
2           evaluation of State newborn screening pro-  
3           grams;

4           “(F) data collection for assessment of new-  
5           born screening programs;

6           “(G) public and provider awareness and  
7           education;

8           “(H) language and terminology used by  
9           State newborn screening programs;

10          “(I) confirmatory testing and verification  
11          of positive results; and

12          “(J) harmonization of laboratory defini-  
13          tions for results that are within the expected  
14          range and results that are outside of the ex-  
15          pected range.”; and

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

17          “(d) DECISION ON RECOMMENDATIONS.—

18                 “(1) IN GENERAL.—Not later than 180 days  
19                 after the Advisory Committee issues a recommenda-  
20                 tion pursuant to this section, the Secretary shall  
21                 adopt or reject such recommendation.

22                 “(2) PENDING RECOMMENDATIONS.—The Sec-  
23                 retary shall adopt or reject any recommendation  
24                 issued by the Advisory Committee that is pending on  
25                 the date of enactment of the Newborn Screening

1 Saves Lives Act of 2007 by not later than 180 days  
2 after the date of enactment of such Act.

3 “(3) DETERMINATIONS TO BE MADE PUBLIC.—  
4 The Secretary shall publicize any determination on  
5 adopting or rejecting a recommendation of the Advi-  
6 sory Committee pursuant to this subsection, includ-  
7 ing the justification for the determination.

8 “(e) CONTINUATION OF OPERATION OF COM-  
9 MITTEE.—Notwithstanding section 14 of the Federal Ad-  
10 visory Committee Act (5 U.S.C. App.), the Advisory Com-  
11 mittee shall continue to operate during the 5-year period  
12 beginning on the date of enactment of the Newborn  
13 Screening Saves Lives Act of 2007.”.

14 **SEC. 7. LABORATORY QUALITY AND SURVEILLANCE.**

15 Part A of title XI of the Public Health Service Act  
16 (42 U.S.C. 300b–1 et seq.) is amended by adding at the  
17 end the following:

18 **“SEC. 1112. LABORATORY QUALITY.**

19 “(a) IN GENERAL.—The Secretary, acting through  
20 the Director of the Centers for Disease Control and Pre-  
21 vention and in consultation with the Advisory Committee  
22 on Heritable Disorders in Newborns and Children estab-  
23 lished under section 1111, shall provide for—

24 “(1) quality assurance for laboratories involved  
25 in screening newborns and children for heritable dis-

1 orders, including quality assurance for newborn-  
2 screening tests, performance evaluation services, and  
3 technical assistance and technology transfer to new-  
4 born screening laboratories to ensure analytic valid-  
5 ity and utility of screening tests; and

6 “(2) population-based pilot testing for new  
7 screening tools for evaluating use on a mass scale.

8 “(b) AUTHORIZATION OF APPROPRIATIONS.—For the  
9 purpose of carrying out this section, there are authorized  
10 to be appropriated \$5,000,000 for fiscal year 2008 and  
11 such sums as may be necessary for each of the fiscal years  
12 2009 through 2012.

13 **“SEC. 1113. SURVEILLANCE PROGRAMS FOR HERITABLE**  
14 **DISORDERS SCREENING.**

15 “(a) IN GENERAL.—The Secretary, acting through  
16 the Director of the Centers for Disease Control and Pre-  
17 vention, in consultation with the Associate Administrator  
18 of the Maternal and Child Health Bureau of the Health  
19 Resources and Services Administration, shall carry out  
20 programs—

21 “(1) to collect, analyze, and make available data  
22 on the heritable disorders recommended by the Advi-  
23 sory Committee on Heritable Disorders in Newborns  
24 and Children established under section 1111, includ-

1 ing data on the causes of such disorders and on the  
2 incidence and prevalence of such disorders;

3 “(2) to operate regional centers for the conduct  
4 of applied epidemiological research on the prevention  
5 of such disorders;

6 “(3) to provide information and education to  
7 the public on the prevention of such disorders; and

8 “(4) to conduct research on and to promote the  
9 prevention of such disorders, and secondary health  
10 conditions among individuals with such disorders.

11 “(b) GRANTS AND CONTRACTS.—

12 “(1) IN GENERAL.—In carrying out subsection  
13 (a), the Secretary may make grants to and enter  
14 into contracts with public and nonprofit private enti-  
15 ties.

16 “(2) SUPPLIES AND SERVICES IN LIEU OF  
17 AWARD FUNDS.—

18 “(A) IN GENERAL.—Upon the request of a  
19 recipient of an award of a grant or contract  
20 under paragraph (1), the Secretary may, sub-  
21 ject to subparagraph (B), provide supplies,  
22 equipment, and services for the purpose of aid-  
23 ing the recipient in carrying out the purposes  
24 for which the award is made and, for such pur-  
25 poses, may detail to the recipient any officer or

1 employee of the Department of Health and  
2 Human Services.

3 “(B) REDUCTION.—With respect to a re-  
4 quest described in subparagraph (A), the Sec-  
5 retary shall reduce the amount of payments  
6 under the award involved by an amount equal  
7 to the costs of detailing personnel and the fair  
8 market value of any supplies, equipment, or  
9 services provided by the Secretary. The Sec-  
10 retary shall, for the payment of expenses in-  
11 curred in complying with such request, expend  
12 the amounts withheld.

13 “(3) APPLICATION FOR AWARD.—The Secretary  
14 may make an award of a grant or contract under  
15 paragraph (1) only if an application for the award  
16 is submitted to the Secretary and the application is  
17 in such form, is made in such manner, and contains  
18 such agreements, assurances, and information as the  
19 Secretary determines to be necessary to carry out  
20 the purposes for which the award is to be made.

21 “(c) BIENNIAL REPORT.—Not later than February  
22 1 of fiscal year 2008 and of every second such year there-  
23 after, the Secretary shall submit to the Committee on En-  
24 ergy and Commerce of the House of Representatives, and  
25 the Committee on Health, Education, Labor, and Pen-

1 sions of the Senate, a report that, with respect to the pre-  
2 ceding 2 fiscal years—

3 “(1) contains information regarding the inci-  
4 dence and prevalence of heritable disorders and the  
5 health status of individuals with such disorders and  
6 the extent to which such disorders have contributed  
7 to the incidence and prevalence of infant mortality  
8 and affected quality of life;

9 “(2) contains information under paragraph (1)  
10 that is specific to various racial and ethnic groups  
11 (including Hispanics, non-Hispanic whites, Blacks,  
12 Native Americans, and Asian Americans);

13 “(3) contains an assessment of the extent to  
14 which various approaches of preventing heritable dis-  
15 orders and secondary health conditions among indi-  
16 viduals with such disorders have been effective;

17 “(4) describes the activities carried out under  
18 this section;

19 “(5) contains information on the incidence and  
20 prevalence of individuals living with heritable dis-  
21 orders, information on the health status of individ-  
22 uals with such disorders, information on any health  
23 disparities experienced by such individuals, and rec-  
24 ommendations for improving the health and wellness  
25 and quality of life of such individuals;

1           “(6) contains a summary of recommendations  
2           from all heritable disorders research conferences  
3           sponsored by the Centers for Disease Control and  
4           Prevention; and

5           “(7) contains any recommendations of the Sec-  
6           retary regarding this section.

7           “(d) APPLICABILITY OF PRIVACY LAWS.—The provi-  
8           sions of this section shall be subject to the requirements  
9           of section 552a of title 5, United States Code. All Federal  
10          laws relating to the privacy of information shall apply to  
11          the data and information that is collected under this sec-  
12          tion.

13          “(e) COORDINATION.—

14                 “(1) IN GENERAL.—In carrying out this sec-  
15                 tion, the Secretary shall coordinate, to the extent  
16                 practicable, programs under this section with pro-  
17                 grams on birth defects and developmental disabilities  
18                 authorized under section 317C.

19                 “(2) PRIORITY IN GRANTS AND CONTRACTS.—  
20                 In making grants and contracts under this section,  
21                 the Secretary shall give priority to entities that dem-  
22                 onstrate the ability to coordinate activities under a  
23                 grant or contract made under this section with exist-  
24                 ing birth defects surveillance activities.

1       “(f) AUTHORIZATION OF APPROPRIATIONS.—For the  
2 purpose of carrying out this section, there are authorized  
3 to be appropriated \$15,000,000 for fiscal year 2008 and  
4 such sums as may be necessary for each of the fiscal years  
5 2009 through 2012.”.

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