

Union Calendar No. 114

107TH CONGRESS
1ST SESSION

H. R. 717

[Report No. 107-195]

To amend the Public Health Service Act to provide for research and services with respect to Duchenne muscular dystrophy.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 14, 2001

Mr. WICKER (for himself, Mr. PETERSON of Minnesota, Mr. GREENWOOD, Mr. TANNER, Mr. EHRLICH, Mr. CRAMER, Mr. GORDON, Mrs. EMERSON, Mr. RILEY, Mr. BRYANT, Mr. FORD, Mr. FOLEY, Ms. HOOLEY of Oregon, Mr. KING, Mr. HOBSON, Mr. PICKERING, Mr. CHAMBLISS, Mr. EHLERS, Mr. TOWNS, Mr. MCGOVERN, Mr. LATOURETTE, Mr. DOOLITTLE, Mr. WATTS of Oklahoma, Ms. GRANGER, Mr. BLUMENAUER, Mr. MURTHA, Mr. OLVER, Mr. BOEHLERT, Mr. GOODLATTE, Mr. HOLDEN, Mr. WATKINS, Mr. COBLE, Mr. ISAKSON, Mr. LOBIONDO, Mr. MCCRERY, Mr. KERNS, Mr. GILMAN, Mr. ROHRBACHER, Mr. ISSA, Mr. CALVERT, Mr. LANGEVIN, Mrs. MEEK of Florida, Mr. HASTINGS of Florida, Ms. BROWN of Florida, Mr. MILLER of Florida, Mr. OTTER, Mr. WALDEN of Oregon, Mrs. MYRICK, Mr. LAHOOD, Mr. LIPINSKI, Mr. LEWIS of Kentucky, Mr. WOLF, Mr. HOSTETTLER, Mr. KINGSTON, Mr. SCARBOROUGH, Mr. UPTON, Mr. LEACH, Mr. GILLMOR, Mr. WALSH, Mr. QUINN, Mr. GANSKE, Mr. JONES of North Carolina, Mr. BACHUS, Mr. OXLEY, Mr. TIAHRT, Mr. WELLER, Mr. MATSUI, Mr. WELDON of Florida, Mr. REYNOLDS, Mr. GUTKNECHT, Mr. CHABOT, Mr. HUNTER, Mr. GOODE, Mr. FLETCHER, Mr. SKELTON, Mr. MORAN of Virginia, Mr. RODRIGUEZ, Mr. TURNER, Mr. BENTSEN, Mr. ABERCROMBIE, Mr. GONZALEZ, Mr. BILIRAKIS, Mr. ARMEY, Mr. MCHUGH, Mr. JENKINS, Mr. BOYD, Mr. PUTNAM, Mr. ROGERS of Michigan, Mr. KELLER, Mrs. KELLY, and Mr. MANZULLO) introduced the following bill; which was referred to the Committee on Energy and Commerce

SEPTEMBER 5, 2001

Additional sponsors: Mr. NEAL of Massachusetts, Mr. STEARNS, Mr. JOHN, Ms. MCCARTHY of Missouri, Mrs. MINK of Hawaii, Mrs. MORELLA, Mrs. LOWEY, Ms. PRYCE of Ohio, Mrs. THURMAN, Mr. BROWN of Ohio, Mr.

SESSIONS, Mr. KOLBE, Mr. RADANOVICH, Mr. BAKER, Mr. HILLEARY, Mr. GRUCCI, Mr. SHOWS, Mr. OBERSTAR, Mr. BONIOR, Mr. LAFALCE, Mr. KANJORSKI, Mr. ALLEN, Mr. HALL of Ohio, Mrs. CAPITO, Mr. WU, Mr. COSTELLO, Mr. HOEKSTRA, Mr. ANDREWS, Mr. ROYCE, Mr. HAYWORTH, Mr. PORTMAN, Mrs. NORTHUP, Mr. SMITH of New Jersey, Mr. STARK, Mr. ETHERIDGE, Mr. TOM DAVIS of Virginia, Mr. SCHAFER, Mr. MICA, Mr. KLECZKA, Mr. GARY MILLER of California, Ms. SLAUGHTER, Mr. SAWYER, Mr. SNYDER, Mr. VITTER, Mr. BARTLETT of Maryland, Mr. BISHOP, Mrs. JO ANN DAVIS of Virginia, Mr. LARSEN of Washington, Mr. BURR of North Carolina, Ms. CARSON of Indiana, Mr. PRICE of North Carolina, Mr. BALDACCI, Mr. SAXTON, Mr. POMEROY, Mr. INSLEE, Mr. PALLONE, Mr. WAMP, Mrs. BONO, Mr. SHIMKUS, Mr. CALLAHAN, Mr. CUNNINGHAM, Mr. RANGEL, Mr. HILLIARD, Mr. BLAGOJEVICH, Mr. GUTIERREZ, Mr. LEWIS of Georgia, Mrs. NAPOLITANO, Mr. WHITFIELD, Mr. GRAVES, Mr. THUNE, Mr. MORAN of Kansas, Mr. ENGLISH, Mr. HORN, Mr. CLEMENT, Mr. TRAFICANT, Mr. McNULTY, Mr. COYNE, Mrs. JONES of Ohio, Mr. BRADY of Pennsylvania, Mr. NETHERCUTT, Mr. CARDIN, Mr. CRANE, Mr. HASTINGS of Washington, Mr. UDALL of New Mexico, Mr. YOUNG of Alaska, Mr. GEORGE MILLER of California, Mr. CRENSHAW, Mr. PENCE, Ms. LOFGREN, Ms. HARMAN, Mr. DUNCAN, Ms. HART, Mr. HAYES, Mr. BOSWELL, Mr. HOYER, Mrs. WILSON, Ms. WOOLSEY, Mr. MOORE, Mr. HILL, Mr. KILDEE, Mr. MOLLOHAN, Mr. WYNN, Mrs. CLAYTON, Mr. BORSKI, Mr. MASCARA, Mr. CONYERS, Mr. KUCINICH, Mr. ACKERMAN, Mr. HINOJOSA, Mr. FROST, Mr. DIAZ-BALART, Mr. MENENDEZ, Mr. SABO, Mr. MATHESON, Mr. PHELPS, Mr. EVANS, Mr. TAYLOR of Mississippi, Mr. FILNER, Ms. VELÁZQUEZ, Mr. McDERMOTT, Ms. BERKLEY, Mrs. TAUSCHER, Mr. ROSS, Mrs. MCCARTHY of New York, Mr. MARKEY, Mr. BARRETT of Wisconsin, Mr. TAYLOR of North Carolina, Mr. NEY, Mr. BARR of Georgia, Mr. BACA, Ms. MILLENDER-McDONALD, Mr. BLUNT, Mr. STUPAK, Mr. LARGENT, Ms. KAPTUR, Ms. DELAURO, Mr. SMITH of Washington, Mr. BONILLA, Mr. TERRY, Mr. FERGUSON, Mr. PAYNE, Mr. MEEHAN, Mr. CARSON of Oklahoma, Ms. SCHAKOWSKY, Mr. SWEENEY, Mr. SMITH of Texas, Mr. LUCAS of Oklahoma, Mr. ADERHOLT, Mr. PLATTS, Mr. GIBBONS, Mr. SERRANO, Mr. EVERETT, Mr. COLLINS, Mr. GILCHREST, Mrs. CUBIN, Mr. CAMP, Mr. BASS, Mr. BALLENGER, Mr. CANTOR, Mr. BRADY of Texas, Mr. CULBERSON, Mr. KIND, Ms. SANCHEZ, Mr. RAMSTAD, Mr. WAXMAN, Mr. LUTHER, Ms. MCCOLLUM, Mr. SUNUNU, Mr. ENGEL, Mr. HUTCHINSON, Mr. ROGERS of Kentucky, Mr. OWENS, Mr. CASTLE, Mr. HOLT, Mr. REYES, Mr. BERRY, Mr. SIMMONS, Ms. ESHOO, Mr. PETERSON of Pennsylvania, Mrs. MALONEY of New York, Mr. LUCAS of Kentucky, Mr. SPRATT, Mr. HEFLEY, Mr. PASTOR, Mr. PASCRELL, Mr. REHBERG, Mr. GALLEGLY, Mr. WELDON of Pennsylvania, Mr. ISRAEL, Mr. HOUGHTON, Mr. KENNEDY of Minnesota, Mr. KIRK, Mr. BOEHNER, Mr. HYDE, Mr. RYAN of Wisconsin, Mrs. BIGGERT, Mr. TIERNEY, Mr. WEINER, Mr. DOOLEY of California, Mr. CONDIT, Mr. BARTON of Texas, Mr. NADLER, Mr. DEAL of Georgia, Mr. FOSSELLA, Mr. GREEN of Texas, Mr. NORWOOD, Mr. DOYLE, Mr. AKIN, Mr. SHADEGG, Mr. FORBES, Mr. RUSH, Mr. NUSSLE, Mr. BUYER, Mrs. CAPPS, Ms. KILPATRICK, Mr. TAUZIN, Mr. BROWN of South Carolina, Ms. BALDWIN, Mr. DEUTSCH, and Mr. WATT of North Carolina

SEPTEMBER 5, 2001

Reported with amendments, committed to the Committee of the Whole House
on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in *italic*]

[For text of introduced bill, see copy of bill as introduced on February 14, 2001]

A BILL

To amend the Public Health Service Act to provide for
research and services with respect to Duchenne muscular
dystrophy.

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 “Muscular Dystrophy*
5 *Community Assistance, Research and Education Amend-*
6 *ments of 2001”, or the “MD-CARE Act”.*

7 **SEC. 2. FINDINGS.**

8 *Congress makes the following findings:*

9 *(1) Of the childhood muscular dystrophies,*
10 *Duchenne Muscular Dystrophy (DMD) is the world’s*
11 *most common and catastrophic form of genetic child-*
12 *hood disease, and is characterized by a rapidly pro-*
13 *gressive muscle weakness that almost always results*
14 *in death, usually by 20 years of age.*

1 (2) *Duchenne muscular dystrophy is genetically*
2 *inherited, and mothers are the carriers in approxi-*
3 *mately 70 percent of all cases.*

4 (3) *If a female is a carrier of the dystrophin*
5 *gene, there is a 50 percent chance per birth that her*
6 *male offspring will have Duchenne muscular dys-*
7 *trophy, and a 50 percent chance per birth that her fe-*
8 *male offspring will be carriers.*

9 (4) *Duchenne is the most common lethal genetic*
10 *disorder of childhood worldwide, affecting approxi-*
11 *mately 1 in every 3,500 boys worldwide.*

12 (5) *Children with muscular dystrophy exhibit ex-*
13 *treme symptoms of weakness, delay in walking, wad-*
14 *dling gait, difficulty in climbing stairs, and progres-*
15 *sive mobility problems often in combination with*
16 *muscle hypertrophy.*

17 (6) *Other forms of muscular dystrophy affecting*
18 *children and adults include Becker, limb girdle, con-*
19 *genital, facioscapulohumeral, myotonic,*
20 *oculopharyngeal, distal, and Emery-Dreifuss mus-*
21 *cular dystrophies.*

22 (7) *Myotonic muscular dystrophy (also known as*
23 *Steinert's disease and dystrophia myotonica) is the*
24 *second most prominent form of muscular dystrophy*
25 *and the type most commonly found in adults. Unlike*

1 *any of the other muscular dystrophies, the muscle*
2 *weakness is accompanied by myotonia (delayed relax-*
3 *ation of muscles after contraction) and by a variety*
4 *of abnormalities in addition to those of muscle.*

5 (8) *Facioscapulohumeral muscular dystrophy*
6 *(referred to in this section as “FSHD”) is a neuro-*
7 *muscular disorder that is inherited genetically and*
8 *has an estimated frequency of 1 in 20,000. FSHD, af-*
9 *fecting between 15,000 to 40,000 persons, causes a*
10 *progressive and sever loss of skeletal muscle gradually*
11 *bringing weakness and reduced mobility. Many per-*
12 *sons with FSHD become severely physically disabled*
13 *and spend many decades in a wheelchair.*

14 (9) *FSHD is regarded as a novel genetic phe-*
15 *nomenon resulting from a crossover of subtelomeric*
16 *DNA and may be the only human disease caused by*
17 *a deletion-mutation.*

18 (10) *Each of the muscular dystrophies, though*
19 *distinct in progressivity and severity of symptoms,*
20 *have a devastating impact on tens of thousands of*
21 *children and adults throughout the United States and*
22 *worldwide and impose severe physical and economic*
23 *burdens on those affected.*

24 (11) *Muscular dystrophies have a significant im-*
25 *pect on quality of life—not only for the individual*

1 *who experiences its painful symptoms and resulting*
2 *disability, but also for family members and care-*
3 *givers.*

4 *(12) Development of therapies for these disorders,*
5 *while realistic with recent advances in research, is*
6 *likely to require costly investments and infrastructure*
7 *to support gene and other therapies.*

8 *(13) There is a shortage of qualified researchers*
9 *in the field of neuromuscular research.*

10 *(14) Many family physicians and health care*
11 *professionals lack the knowledge and resources to de-*
12 *tect and properly diagnose the disease as early as pos-*
13 *sible, thus exacerbating the progressiveness of symp-*
14 *toms in cases that go undetected or misdiagnosed.*

15 *(15) There is a need for efficient mechanisms to*
16 *translate clinically relevant findings in muscular dys-*
17 *trophy research from basic science to applied work.*

18 *(16) Educating the public and health care com-*
19 *munity throughout the country about this devastating*
20 *disease is of paramount importance and is in every*
21 *respect in the public interest and to the benefit of all*
22 *communities.*

1 **SEC. 3. EXPANSION, INTENSIFICATION, AND COORDINA-**
2 **TION OF ACTIVITIES OF NATIONAL INSTI-**
3 **TUTES OF HEALTH WITH RESPECT TO RE-**
4 **SEARCH ON MUSCULAR DYSTROPHY.**

5 *Part A of title IV of the Public Health Service Act*
6 *(42 U.S.C. 281 et seq.) is amended by adding at the end*
7 *the following:*

8 **“SEC. 404E. MUSCULAR DYSTROPHY; INITIATIVE THROUGH**
9 **DIRECTOR OF NATIONAL INSTITUTES OF**
10 **HEALTH.**

11 *“(a) EXPANSION, INTENSIFICATION, AND COORDINA-*
12 *TION OF ACTIVITIES.—*

13 *“(1) IN GENERAL.—The Director of NIH, in co-*
14 *ordination with the Directors of the National Insti-*
15 *tute of Neurological Disorders and Stroke, the Na-*
16 *tional Institute of Arthritis and Musculoskeletal and*
17 *Skin Diseases, the National Institute of Child Health*
18 *and Human Development, and the other national re-*
19 *search institutes as appropriate, shall expand and in-*
20 *tensify programs of such Institutes with respect to re-*
21 *search and related activities concerning various forms*
22 *of muscular dystrophy, including Duchenne,*
23 *myotonic, facioscapulohumeral muscular dystrophy*
24 *(referred to in this section as ‘FSHD’) and other*
25 *forms of muscular dystrophy.*

1 “(2) *COORDINATION.*—*The Directors referred to*
2 *in paragraph (1) shall jointly coordinate the pro-*
3 *grams referred to in such paragraph and consult with*
4 *the Muscular Dystrophy Interagency Coordinating*
5 *Committee established under section 6 of the MD-*
6 *CARE Act.*

7 “(3) *ALLOCATIONS BY DIRECTOR OF NIH.*—*The*
8 *Director of NIH shall allocate the amounts appro-*
9 *priated to carry out this section for each fiscal year*
10 *among the national research institutes referred to in*
11 *paragraph (1).*

12 “(b) *CENTERS OF EXCELLENCE.*—

13 “(1) *IN GENERAL.*—*The Director of NIH shall*
14 *award grants and contracts under subsection (a)(1) to*
15 *public or nonprofit private entities to pay all or part*
16 *of the cost of planning, establishing, improving, and*
17 *providing basic operating support for centers of excel-*
18 *lence regarding research on various forms of muscular*
19 *dystrophy.*

20 “(2) *RESEARCH.*—*Each center under paragraph*
21 *(1) shall supplement but not replace the establishment*
22 *of a comprehensive research portfolio in all the mus-*
23 *cular dystrophies. As a whole, the centers shall con-*
24 *duct basic and clinical research in all forms of mus-*
25 *cular dystrophy including early detection, diagnosis,*

1 *prevention, and treatment, including the fields of*
2 *muscle biology, genetics, noninvasive imaging, genet-*
3 *ics, pharmacological and other therapies.*

4 “(3) *COORDINATION OF CENTERS; REPORTS.—*

5 *The Director of NIH—*

6 “(A) *shall, as appropriate, provide for the*
7 *coordination of information among centers under*
8 *paragraph (1) and ensure regular communica-*
9 *tion between such centers; and*

10 “(B) *shall require the periodic preparation*
11 *of reports on the activities of the centers and the*
12 *submission of the reports to the Director.*

13 “(4) *ORGANIZATION OF CENTERS.—Each center*
14 *under paragraph (1) shall use the facilities of a single*
15 *institution, or be formed from a consortium of cooper-*
16 *ating institutions, meeting such requirements as may*
17 *be prescribed by the Director of NIH.*

18 “(5) *DURATION OF SUPPORT.—Support for a*
19 *center established under paragraph (1) may be pro-*
20 *vided under this section for a period of not to exceed*
21 *5 years. Such period may be extended for 1 or more*
22 *additional periods not exceeding 5 years if the oper-*
23 *ations of such center have been reviewed by an appro-*
24 *prate technical and scientific peer review group es-*
25 *tablished by the Director of NIH and if such group*

1 *has recommended to the Director that such period*
2 *should be extended.*

3 “(c) *FACILITATION OF RESEARCH.*—*The Director of*
4 *NIH shall provide for a program under subsection (a)(1)*
5 *under which samples of tissues and genetic materials that*
6 *are of use in research on muscular dystrophy are donated,*
7 *collected, preserved, and made available for such research.*
8 *The program shall be carried out in accordance with accept-*
9 *ed scientific and medical standards for the donation, collec-*
10 *tion, and preservation of such samples.*

11 “(d) *COORDINATING COMMITTEE.*—

12 “(1) *IN GENERAL.*—*The Secretary shall establish*
13 *the Muscular Dystrophy Coordinating Committee (re-*
14 *ferred to in this section as the ‘Coordinating Com-*
15 *mittee’)* *to coordinate activities across the National*
16 *Institutes and with other Federal health programs*
17 *and activities relating to the various forms of mus-*
18 *cular dystrophy.*

19 “(2) *COMPOSITION.*—*The Coordinating Com-*
20 *mittee shall consist of not more than 15 members to*
21 *be appointed by the Secretary, of which—*

22 “(A) $\frac{2}{3}$ *of such members shall represent*
23 *governmental agencies, including the directors or*
24 *their designees of each of the national research*
25 *institutes involved in research with respect to*

1 *muscular dystrophy and representatives of all*
2 *other Federal departments and agencies whose*
3 *programs involve health functions or responsibil-*
4 *ities relevant to such diseases, including the Cen-*
5 *ters for Disease Control and Prevention, the*
6 *Health Resources and Services Administration*
7 *and the Food and Drug Administration and rep-*
8 *resentatives of other governmental agencies that*
9 *serve children with muscular dystrophy, such as*
10 *the Department of Education; and*

11 “(B) $\frac{1}{3}$ of such members shall be public
12 members, including a broad cross section of per-
13 sons affected with muscular dystrophies includ-
14 ing parents or legal guardians, affected individ-
15 uals, researchers, and clinicians.

16 *Members appointed under subparagraph (B) shall*
17 *serve for a term of 3 years, and may serve for an un-*
18 *limited number of terms if reappointed.*

19 “(3) CHAIR.—

20 “(A) IN GENERAL.—With respect to mus-
21 cular dystrophy, the Chair of the Coordinating
22 Committee shall serve as the principal advisor to
23 the Secretary, the Assistant Secretary for Health,
24 and the Director of NIH, and shall provide ad-
25 vice to the Director of the Centers for Disease

1 *Control and Prevention, the Commissioner of*
2 *Food and Drugs, and to the heads of other rel-*
3 *evant agencies. The Coordinating Committee*
4 *shall select the Chair for a term not to exceed 2*
5 *years.*

6 “(B) *APPOINTMENT.*—*The Chair of the*
7 *Committee shall be appointed by and be directly*
8 *responsible to the Secretary.*

9 “(4) *ADMINISTRATIVE SUPPORT; TERMS OF*
10 *SERVICE; OTHER PROVISIONS.*—*The following shall*
11 *apply with respect to the Coordinating Committee:*

12 “(A) *The Coordinating Committee shall re-*
13 *ceive necessary and appropriate administrative*
14 *support from the Department of Health and*
15 *Human Services.*

16 “(B) *The Coordinating Committee shall*
17 *meet as appropriate as determined by the Sec-*
18 *retary, in consultation with the chair.*

19 “(e) *PLAN FOR HHS ACTIVITIES.*—

20 “(1) *IN GENERAL.*—*Not later than 1 year after*
21 *the date of enactment of this section, the Coordinating*
22 *Committee shall develop a plan for conducting and*
23 *supporting research and education on muscular dys-*
24 *trophy through the national research institutes and*

1 *shall periodically review and revise the plan. The*
2 *plan shall—*

3 “(A) *provide for a broad range of research*
4 *and education activities relating to biomedical,*
5 *epidemiological, psychosocial, and rehabilitative*
6 *issues, including studies of the impact of such*
7 *diseases in rural and underserved communities;*

8 “(B) *identify priorities among the pro-*
9 *grams and activities of the National Institutes of*
10 *Health regarding such diseases; and*

11 “(C) *reflect input from a broad range of sci-*
12 *entists, patients, and advocacy groups.*

13 “(2) *CERTAIN ELEMENTS OF PLAN.—The plan*
14 *under paragraph (1) shall, with respect to each form*
15 *of muscular dystrophy, provide for the following as*
16 *appropriate:*

17 “(A) *Research to determine the reasons un-*
18 *derlying the incidence and prevalence of various*
19 *forms of muscular dystrophy.*

20 “(B) *Basic research concerning the etiology*
21 *and genetic links of the disease and potential*
22 *causes of mutations.*

23 “(C) *The development of improved screening*
24 *techniques.*

1 “(D) *Basic and clinical research for the de-*
2 *velopment and evaluation of new treatments, in-*
3 *cluding new biological agents.*

4 “(E) *Information and education programs*
5 *for health care professionals and the public.*

6 “(f) *REPORTS TO CONGRESS.—The Coordinating*
7 *Committee shall biennially submit to the Committee on En-*
8 *ergy and Commerce of the House of Representatives, and*
9 *the Committee on Health, Education, Labor, and Pensions*
10 *of the Senate, a report that describes the research, edu-*
11 *cation, and other activities on muscular dystrophy being*
12 *conducted or supported through the Department of Health*
13 *and Human Services. Each such report shall include the*
14 *following:*

15 “(1) *The plan under subsection (e)(1) (or revi-*
16 *sions to the plan, as the case may be).*

17 “(2) *Provisions specifying the amounts expended*
18 *by the Department of Health and Human Services*
19 *with respect to various forms of muscular dystrophy,*
20 *including Duchenne, myotonic, FSHD and other*
21 *forms of muscular dystrophy.*

22 “(3) *Provisions identifying particular projects or*
23 *types of projects that should in the future be consid-*
24 *ered by the national research institutes or other enti-*

1 *ties in the field of research on all muscular dys-*
2 *trophies.*

3 “(g) *PUBLIC INPUT.—The Secretary shall, under sub-*
4 *section (a)(1), provide for a means through which the public*
5 *can obtain information on the existing and planned pro-*
6 *grams and activities of the Department of Health and*
7 *Human Services with respect to various forms of muscular*
8 *dystrophy and through which the Secretary can receive*
9 *comments from the public regarding such programs and ac-*
10 *tivities.*

11 “(h) *AUTHORIZATION OF APPROPRIATIONS.—For the*
12 *purpose of carrying out this section, there are authorized*
13 *to be appropriated such sums as may be necessary for each*
14 *of fiscal years 2002 through 2006. The authorization of ap-*
15 *propriations established in the preceding sentence is in ad-*
16 *dition to any other authorization of appropriations that is*
17 *available for conducting or supporting through the National*
18 *Institutes of Health research and other activities with re-*
19 *spect to muscular dystrophy.”.*

1 **SEC. 4. DEVELOPMENT AND EXPANSION OF ACTIVITIES OF**
2 **CENTERS FOR DISEASE CONTROL AND PRE-**
3 **VENTION WITH RESPECT TO EPIDEMIOLOG-**
4 **ICAL RESEARCH ON MUSCULAR DYSTROPHY.**

5 *Part B of title III of the Public Health Service Act*
6 *(42 U.S.C. 243 et seq.) is amended by inserting after section*
7 *317P the following:*

8 **“SEC. 317Q. SURVEILLANCE AND RESEARCH REGARDING**
9 **MUSCULAR DYSTROPHY.**

10 *“(a) IN GENERAL.—The Secretary, acting through the*
11 *Director of the Centers for Disease Control and Prevention,*
12 *may award grants and cooperative agreements to public or*
13 *nonprofit private entities (including health departments of*
14 *States and political subdivisions of States, and including*
15 *universities and other educational entities) for the collec-*
16 *tion, analysis, and reporting of data on Duchenne and*
17 *other forms of muscular dystrophy. In making such awards,*
18 *the Secretary may provide direct technical assistance in*
19 *lieu of cash.*

20 *“(b) NATIONAL MUSCULAR DYSTROPHY EPIDEMI-*
21 *LOGY PROGRAM.—The Secretary, acting through the Di-*
22 *rector of the Centers for Disease Control and Prevention,*
23 *may award grants to public or nonprofit private entities*
24 *(including health departments of States and political sub-*
25 *divisions of States, and including universities and other*
26 *educational entities) for the purpose of carrying out epide-*

1 *miological activities regarding Duchenne and other forms*
2 *of muscular dystrophies, including collecting and analyzing*
3 *information on the number, incidence, correlates, and*
4 *symptoms of cases. In carrying out the preceding sentence,*
5 *the Secretary shall provide for a national surveillance pro-*
6 *gram. In making awards under this subsection, the Sec-*
7 *retary may provide direct technical assistance in lieu of*
8 *cash.*

9 “(c) *COORDINATION WITH CENTERS OF EXCEL-*
10 *LLENCE.—The Secretary shall ensure that epidemiological*
11 *information under subsections (a) and (b) is made available*
12 *to centers of excellence supported under section 404E(b) by*
13 *the Director of the National Institutes of Health.*

14 “(d) *AUTHORIZATION OF APPROPRIATIONS.—There*
15 *are authorized to be appropriated such sums as may be nec-*
16 *essary to carry out this section.”.*

17 **SEC. 5. INFORMATION AND EDUCATION.**

18 (a) *IN GENERAL.—The Secretary of Health and*
19 *Human Services (referred to in this Act as the “Secretary”)*
20 *shall establish and implement a program to provide infor-*
21 *mation and education on muscular dystrophy to health pro-*
22 *fessionals and the general public, including information*
23 *and education on advances in the diagnosis and treatment*
24 *of muscular dystrophy and training and continuing edu-*
25 *cation through programs for scientists, physicians, medical*

1 *students, and other health professionals who provide care*
2 *for patients with muscular dystrophy.*

3 (b) *STIPENDS.—The Secretary may use amounts made*
4 *available under this section provides stipends for health*
5 *professionals who are enrolled in training programs under*
6 *this section.*

7 (c) *AUTHORIZATION OF APPROPRIATIONS.—There are*
8 *authorized to be appropriated such sums as may be nec-*
9 *essary to carry out this section.*

10 **SEC. 6. REPORT TO CONGRESS.**

11 *Not later than January 1, 2003, and each January*
12 *1 thereafter, the Secretary shall prepare and submit to the*
13 *appropriate committees of Congress, a report concerning the*
14 *implementation of this Act and the amendments made by*
15 *this Act.*

Amend the title so as to read: “A bill to amend the Public Health Service Act to provide for research with respect to various forms of muscular dystrophy, including Duchenne, Becker, limb girdle, congenital, facioscapulohumeral, myotonic, oculopharyngeal, distal, and Emery-Dreifuss muscular dystrophies.”.

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107TH CONGRESS
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H. R. 717

[Report No. 107-195]

A BILL

To amend the Public Health Service Act to provide for research and services with respect to Duchenne muscular dystrophy.

SEPTEMBER 5, 2001

Reported with amendments, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed