I

111TH CONGRESS
1ST SESSION

# H. R. 3754

To amend the Public Health Service Act with regard to research on asthma, and for other purposes.

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IN THE HOUSE OF REPRESENTATIVES

OCTOBER 7, 2009

Mrs. MCCARTHY of New York 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 with regard to research on asthma, 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 ''Family Asthma Act''.

5 **SEC. 2. FINDINGS.**

6 The Congress makes the following findings:
7 (1) The number of people with asthma more
8 than doubled between 1980 and 1995. According to
9 the Centers for Disease Control and Prevention, in
10 2007 more than 34,000,000 Americans had been di-

1 agnosed with asthma, including an estimated
2 9,600,000 children. Asthma rates are highest among
3 Puerto Rican populations. Rates were 140 percent
4 greater among Puerto Rican children compared to
5 non-Hispanic White children. Asthma strikes 1 in 13
6 Americans.
7 (2) According to the Centers for Disease Con-
8 trol and Prevention, in 2005 more than 3,800 Amer-
9 icans died from asthma. The rate of mortality from
10 asthma is higher among African-Americans and
11 women.
12 (3) The Centers for Disease Control and Pre-
13 vention report that asthma accounted for more than
14 440,000 hospitalizations and more than 1,600,000
15 visits to hospital emergency departments in 2006.
16 The rate for asthma-related emergency room visits is
17 500 percent greater and hospitalization rates are
18 300 percent higher for Blacks compared to Whites.
19 (4) According to the National Heart, Lung, and
20 Blood Institute of the National Institutes of Health,
21 the annual cost of asthma to the United States is
22 approximately $19,700,000,000.
23 (5) According to the Centers for Disease Con-
24 trol and Prevention, almost 13,000,000 school days

1 and 10,000,000 work days are missed annually as a
2 result of asthma.

3 (6) Asthma episodes can be triggered by both
4 outdoor air pollution and indoor air pollution, in-
5 cluding pollutants such as cigarette smoke and com-
6 bustion by-products. Asthma episodes can also be
7 triggered by indoor allergens such as animal dander
8 and outdoor allergens such as pollen and molds.

9 (7) Public health interventions and medical care
10 in accordance with existing guidelines have been
11 proven effective in the treatment and management
12 of asthma. Better asthma management could reduce
13 the numbers of emergency department visits and
14 hospitalizations due to asthma. Studies published in
15 medical journals have shown that better asthma
16 management results in improved asthma outcomes
17 at a lower cost.

18 (8) In 2005, the Centers for Disease Control
19 and Prevention cited ''the urgent need'' for en-
20 hanced public health surveillance data regarding
21 asthma, noting that the current system has led to a
22 ''patchwork of health effect measures''. National
23 data are needed to allow comparisons at smaller geo-
24 graphic levels, such as counties, and to better under-
25 stand the groups at risk.

1 (9) The alarming rise in the prevalence of asth-
2 ma, its adverse effect on school attendance and pro-
3 ductivity, and its cost for hospitalizations and emer-
4 gency room visits, argue for a more vigorous Federal
5 leadership role, including increasing awareness of
6 asthma as a chronic illness, its symptoms, the role
7 of both indoor and outdoor environmental factors
8 that exacerbate the disease, and other factors that
9 affect its exacerbations and severity. The goals of
10 the Government and its partners in the nonprofit
11 and private sectors should include reducing the num-
12 ber and severity of asthma attacks, asthma's finan-
13 cial burden, and the health disparities associated
14 with asthma.

15 **SEC. 3. FAMILY ASTHMA CLINICAL AND ENVIRONMENTAL**
16 **HEALTH RESEARCH GRANTS.**

17 Part P of title III of the Public Health Service Act
18 (42 U.S.C. 280g et seq.) is amended—
19 (1) by redesignating the second and third sec-
20 tions 399R (added by Public Laws 110–373 and
21 110–374, respectively) as sections 399S and 399T;
22 and
23 (2) by adding at the end the following:

1 **"SEC. 399U. FAMILY ASTHMA CLINICAL AND ENVIRON-**
2 **MENTAL HEALTH RESEARCH GRANT PRO-**
3 **GRAM.**

4 "(a) PURPOSE.—The purpose of this section is to au-
5 thorize the National Institutes of Health to award grants
6 to carry out pilot projects to prevent and control asthma
7 symptoms and to reduce asthma attacks and improve pa-
8 tient self-management for individuals and in families con-
9 taining individuals with asthma including—

10 "(1) utilizing electronic health records, tele-
11 health, and other novel electronic communications to
12 prevent acute asthma attacks, and to improve asth-
13 ma surveillance activities as described under section
14 317I(c); and

15 "(2) expanding the understanding of environ-
16 mental and other factors that cause and contribute
17 to the burden of asthma.

18 "(b) GRANTS.—

19 "(1) IN GENERAL.—The Secretary, acting
20 through the Director of the National Institutes of
21 Health, shall award grants to eligible entities to
22 carry out pilot projects consistent with the activities
23 described in subsection (a).

24 "(2) AWARDING OF GRANTS.—In awarding the
25 grants under paragraph (1), the Secretary shall—

1 ''(A) give priority to entities that serve disproportionately impacted populations; and

3 ''(B) give consideration to an adequate national understanding of asthma prevalence, so as to gain better information about asthma at the national level.

7 ''(3) COORDINATION OF AGENCIES.—The National Heart, Lung, and Blood Institute (which shall be the lead agency for purposes of activities carried out under this section), in coordination with the National Institute of Environmental Health Sciences, the National Institute of Allergy and Infectious Diseases, and the National Institute of Child Health and Human Development, shall administer grants to be utilized by entities performing research of the type described in subsection (a). Such institutes shall coordinate in writing a request for applications, reviewing applications, and providing administrative oversight for the program carried out under this section.

21 ''(c) ELIGIBILITY.—To be eligible to receive a grant under subsection (b), an entity shall be—

23 ''(1) a hospital, including a children's hospital;

24 ''(2) a community health center;

25 ''(3) a medical school;

1 ‘‘(4) a nonprofit institution; or
2 ‘‘(5) another entity, as designated by the Sec-
3 retary.
4 ‘‘(d) APPLICATION.—
5 ‘‘(1) IN GENERAL.—An eligible entity shall sub-
6 mit an application to the Director of the National
7 Institutes of Health for a grant under this section
8 at such time, in such manner, and accompanied by
9 such information as such Director may require.
10 ‘‘(2) REQUIRED INFORMATION.—An application
11 submitted under this subsection shall, as is applica-
12 ble and practicable to the area and scope of the pilot
13 project—
14 ‘‘(A) include information demonstrating
15 the prevalence of chronic asthma among the
16 population to be served by the applicant on at
17 least a State-level basis and where practicable,
18 in areas and localities within the State;
19 ‘‘(B) provide assurance that the applicant
20 will establish consistent communication with pa-
21 tients, including using the Internet or telephone
22 for the prompt transmission of patient informa-
23 tion related to symptoms and conditions, such
24 as peak flowmeter measurements;

"(C) provide assurance that enrollees will have baseline and ongoing medical data collected, including data related to pulmonary function and skin or in vitro testing for sensitization to allergies;

"(D) propose novel approaches to studying the gene-environment interaction of the patients and have the capacity to engage in such data collection, or partner with an institution with such a capacity;

"(E) contain assurances that the applicant will communicate in a manner designed to preserve patient confidentiality, with at least 1 of the asthma clinical centers of the National Institutes of Health; and

"(F) provide assurances that the applicant can effectively coordinate care between physicians, including asthma specialists, nurses, allied health professionals, community health workers, nonprofit organizations, and the other entities responsible for implementing the pilot project involved.

"(3) COLLABORATION WITH LOCAL INSTITUTIONS.—An eligible entity receiving a grant under this section is encouraged to—

1 "(A) collaborate with 1 or more Head
2 Start programs to identify children and families
3 with asthma within the geographic area of the
4 applicant;
5 "(B) collaborate with local school districts
6 to recruit children with physician-diagnosed
7 asthma; and
8 "(C) partner with local, community-based
9 nonprofit organizations to identify children and
10 families with asthma within the geographic area
11 of the entity.
12 "(e) USE OF FUNDS.—
13 "(1) IN GENERAL.—An eligible entity shall use
14 amounts received under a grant under this section to
15 carry out the purpose described in subsection (a), in-
16 cluding—
17 "(A) conducting an assessment of the pa-
18 tients served to determine possible contributors
19 to asthma exacerbations in the indoor and out-
20 door environments, including exposure to diesel
21 and other particles, ozone and other gases, gas-
22 eous pollutants and allergens, mold, chemicals
23 found in the home or workplace, and other in-
24 door pollutants;

1 "(B) implementing interventions regarding
2 indoor and outdoor environments to reduce the
3 severity and persistence of asthma;
4 "(C) developing and maintaining question-
5 naires completed by the patients, or the parents
6 or guardians of the patients, regarding their re-
7 spective occupations and personal exposure his-
8 tory, in order to increase the understanding of
9 factors that contribute to asthma prevalence;
10 and
11 "(D) conducting other research as des-
12 ignated by the Director of the National Insti-
13 tutes of Health, particularly in areas that will
14 advance knowledge of the factors that con-
15 tribute to asthma.
16 "(2) RESEARCH OF SIGNIFICANT INTEREST.—
17 An eligible entity receiving a grant under this sec-
18 tion is encouraged to conduct research under this
19 section on the interactions between environmental
20 exposures and genetic susceptibilities that contribute
21 to the development or exacerbation of asthma.
22 "(f) PROTECTION OF INFORMATION.—The Secretary
23 shall ensure the implementation of protections of indi-
24 vidual health privacy under this section consistent with the
25 regulations promulgated under section 264(c) of the

Health Insurance Portability and Accountability Act of 1996.

"(g) REPORT.—The Secretary shall submit a report to the Congress on the success of and the next steps resulting from the pilot projects funded under this section not later than 5 years after the date of the enactment of this section.

"(h) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated such sums as may be necessary for each of fiscal years 2010 through 2014 to carry out this section.".

**SEC. 4. NATIONAL ASTHMA EDUCATION AND PREVENTION PROGRAM OF THE NATIONAL HEART, LUNG, AND BLOOD INSTITUTE.**

Part C of title IV of the Public Health Service Act (42 U.S.C. 285 et seq.) is amended by inserting after section 424C the following:

**"SEC. 424D. EXPANSION OF THE NATIONAL ASTHMA EDUCATION AND PREVENTION PROGRAM.**

"(a) DEVELOPMENT OF A NATIONAL ASTHMA ACTION PLAN.—

"(1) IN GENERAL.—In addition to any other authorization of appropriation available to the National Heart, Lung, and Blood Institute for the purpose of carrying out the National Asthma Education

1 and Prevention Program (referred to in this section
2 as the 'program'), there is authorized to be appro-
3 priated to such Institute such sums as may be nec-
4 essary for each of fiscal years 2010 through 2014 to
5 develop a National Asthma Action Plan.

6 "(2) USE OF APPROPRIATIONS.—The amounts
7 appropriated pursuant to paragraph (1) shall be
8 used to fund the report by the program described
9 under subsection (b).

10 "(b) REPORT TO CONGRESS.—

11 "(1) IN GENERAL.—Not later than 2 years
12 after the date of the enactment of the Family Asth-
13 ma Act, the program shall, in consultation with pa-
14 tient groups, nonprofit organizations, medical soci-
15 eties, and other relevant governmental and non-
16 governmental entities that participate in the pro-
17 gram, submit to the Congress a report that—

18 "(A) catalogs, with respect to asthma pre-
19 vention, management, and surveillance—

20 "(i) the activities of the Federal Gov-
21 ernment, including an assessment of the
22 progress of the Federal Government and
23 States, with respect to achieving the goals
24 of the Healthy People 2020 initiative; and

1 "(ii) the activities of other entities
2 that participate in the program, including
3 nonprofit organizations, patient advocacy
4 groups, and medical societies; and
5 "(B) makes recommendations for the fu-
6 ture direction of asthma activities, in consulta-
7 tion with researchers from the National Insti-
8 tutes of Health and other member bodies of the
9 National Asthma Education and Prevention
10 Program who are qualified to review and ana-
11 lyze data and evaluate interventions, includ-
12 ing—
13 "(i) description of how the Federal
14 Government may improve its response to
15 asthma including identifying any barriers
16 that may exist;
17 "(ii) description of how the Federal
18 Government may continue, expand, and
19 improve its private-public partnerships
20 with respect to asthma including identi-
21 fying any barriers that may exist;
22 "(iii) identification of steps that may
23 be taken to reduce the—
24 "(I) morbidity, mortality, and
25 overall prevalence of asthma;

1 “(II) financial burden of asthma
2 on society;
3 “(III) burden of asthma on dis-
4 proportionately affected areas, par-
5 ticularly those in medically under-
6 served populations (as defined in sec-
7 tion 330(b)(3)); and
8 “(IV) burden of asthma as a
9 chronic disease;
10 “(iv) identification of programs and
11 policies that have achieved the steps de-
12 scribed under clause (iii), and steps that
13 may be taken to expand such programs
14 and policies to benefit larger populations;
15 and
16 “(v) recommendations for future re-
17 search and interventions.
18 “(2) UPDATES TO CONGRESS.—
19 “(A) CONGRESSIONAL REQUEST.—During
20 the 5-year period following the submission of
21 the report under paragraph (1), the program
22 shall submit updates and revisions of the report
23 upon the request of the Congress.
24 “(B) FIVE-YEAR REEVALUATION.—At the
25 end of the 5-year period following the submis-

1 sion of the report under paragraph (1), the pro-
2 gram shall evaluate its analyses and rec-
3 ommendations under such report and determine
4 whether a new report to the Congress is nec-
5 essary, and make appropriate recommendations
6 to the Congress.''.

7 **SEC. 5. ASTHMA–RELATED ACTIVITIES OF THE CENTERS**
8 **FOR DISEASE CONTROL AND PREVENTION.**

9 Section 317I of the Public Health Service Act (42
10 U.S.C. 247b–10) is amended to read as follows:

11 **''SEC. 317I. ASTHMA-RELATED ACTIVITIES OF THE CENTERS**
12 **FOR DISEASE CONTROL AND PREVENTION.**

13 ''(a) PROGRAM FOR PROVIDING INFORMATION AND
14 EDUCATION TO THE PUBLIC.—The Secretary, acting
15 through the Director of the Centers for Disease Control
16 and Prevention, shall collaborate with State and local
17 health departments to conduct activities, including the
18 provision of information and education to the public re-
19 garding asthma including—

20 ''(1) deterring the harmful consequences of un-
21 controlled asthma; and

22 ''(2) disseminating health education and infor-
23 mation regarding prevention of asthma episodes and
24 strategies for managing asthma.

1 "(b) DEVELOPMENT OF STATE ASTHMA PLANS.—
2 The Secretary, acting through the Director of the Centers
3 for Disease Control and Prevention, shall collaborate with
4 State and local health departments to develop State plans
5 incorporating public health responses to reduce the burden
6 of asthma, particularly regarding disproportionately af-
7 fected populations.

8 "(c) COMPILATION OF DATA.—The Secretary, acting
9 through the Director of the Centers for Disease Control
10 and Prevention, shall, in cooperation with State and local
11 public health officials—

12 "(1) conduct asthma surveillance activities to
13 collect data on the prevalence and severity of asth-
14 ma, the effectiveness of public health asthma inter-
15 ventions, and the quality of asthma management, in-
16 cluding—

17 "(A) collection of household data on the
18 local burden of asthma;

19 "(B) surveillance of health care facilities;
20 and

21 "(C) collection of data not containing indi-
22 vidually identifiable information from electronic
23 health records or other electronic communica-
24 tions;

1 "(2) compile and annually publish data regard-
2 ing the prevalence and incidence of childhood asth-
3 ma, the child mortality rate, and the number of hos-
4 pital admissions and emergency department visits by
5 children associated with asthma nationally and in
6 each State and at the county level by age, sex, race,
7 and ethnicity, as well as lifetime and current preva-
8 lence; and

9 "(3) compile and annually publish data regard-
10 ing the prevalence and incidence of adult asthma,
11 the adult mortality rate, and the number of hospital
12 admissions and emergency department visits by
13 adults associated with asthma nationally and in each
14 State and at the county level by age, sex, race, eth-
15 nicity, industry, and occupation, as well as lifetime
16 and current prevalence.

17 "(d) COORDINATION OF DATA COLLECTION.—The
18 Director of the Centers for Disease Control and Preven-
19 tion, in conjunction with State and local health depart-
20 ments, shall coordinate data collection activities under
21 subsection (c)(2) so as to maximize comparability of re-
22 sults.

23 "(e) COLLABORATION.—

24 "(1) IN GENERAL.—The Centers for Disease
25 Control and Prevention are encouraged to collabo-

1 rate with national, State, and local nonprofit organi-
2 zations to provide information and education about
3 asthma, and to strengthen such collaborations when
4 possible.

5 ''(2) SPECIFIC ACTIVITIES.—The Division of
6 Adolescent and School Health is encouraged to ex-
7 pand its activities with non-Federal partners, espe-
8 cially State-level entities.

9 ''(f) ADDITIONAL FUNDING.—In addition to any
10 other authorization of appropriations that is available to
11 the Centers for Disease Control and Prevention for the
12 purpose of carrying out this section, there is authorized
13 to be appropriated to such Centers such sums as may be
14 necessary for each of fiscal years 2010 through 2014 for
15 the purpose of carrying out this section.''.

○