116th CONGRESS 1st Session



To authorize the Secretary of Health and Human Services to carry out activities relating to neglected diseases of poverty.

#### IN THE SENATE OF THE UNITED STATES

Mr. BOOKER introduced the following bill; which was read twice and referred to the Committee on \_\_\_\_\_

### A BILL

To authorize the Secretary of Health and Human Services to carry out activities relating to neglected diseases of poverty.

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 "Study, Treat, Observe,
- 5 and Prevent Neglected Diseases of Poverty Act" or the

6 "STOP Neglected Diseases of Poverty Act".

#### 7 SEC. 2. FINDINGS.

8 Congress finds as follows:

9 (1) Neglected diseases of poverty, which are
10 also known as "neglected tropical diseases", are a
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1	group of diseases that disproportionately affect vul-
2	nerable populations living in extreme poverty.
3	(2) More than $1,000,000,000$ people worldwide
4	are affected by neglected diseases of poverty.
5	(3) Neglected diseases of poverty can be trans-
6	mitted—
7	(A) through contaminated food, water, and
8	soil;
9	(B) through parasites, insects, blood trans-
10	fusion, and organ transplant; and
11	(C) in some cases, congenitally.
12	(4) Neglected diseases of poverty have a high
13	rate of morbidity and mortality and can lead to
14	health complications such as heart disease, epilepsy,
15	asthma, blindness, developmental delays, stillbirth,
16	low birthweight, and gastrointestinal disorders.
17	(5) Some neglected diseases of poverty can be
18	asymptomatic at the outset, but debilitating or dan-
19	gerous symptoms can emerge over time or under cer-
20	tain conditions, such as pregnancy. It is estimated
21	that millions of people are living with these diseases
22	and are not aware that they are infected.
23	(6) For tens of thousands of individuals, dis-
24	eases of poverty that are chronic and neglected can
25	manifest into severe illness later in life.

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1 (7) Neglected diseases of poverty place a sig-2 nificant financial burden on affected individuals and 3 communities due to the health care costs associated 4 with these diseases and because these diseases limit 5 individuals' productivity and ability to be active con-6 tributors to their communities. This burden could 7 largely be prevented through early screening and 8 treatment, which are highly cost effective.

9 (8) Since its inception in 2006, the Neglected 10 Tropical Diseases Program at the United States 11 Agency for International Development and its part-12 ners, including the Centers for Disease Control and 13 Prevention, have delivered more than 1,600,000,000 14 treatments to more than 743,000,000 people.

(9) Due to the support provided by the United
States Agency for International Development and its
partners, 140,000,000 people live in regions where
they are no longer at risk of contracting lymphatic
filariasis, and 65,000,000 people live in regions
where they are no longer at risk of contracting trachoma.

(10) Although the exact prevalence and burden
of these diseases in the United States is unknown
because of stigma and limited reporting, surveillance, and awareness, one study estimates that there

are 12,000,000 individuals living with a neglected
 disease of poverty throughout the country. These
 diseases disproportionately affect racial and ethnic
 minorities living in poverty and in regions where
 water quality and sanitation are substandard.

6 (11) The major neglected diseases of poverty in 7 the United States that predominantly occur among 8 those living in poverty are the following: 9 Toxocariasis, cysticercosis, Chagas disease, toxoplas-10 mosis, trichomoniasis, and Dengue Fever.

(12) There is a lack of diagnostic and treatment programs, including for early diagnosis and treatment, for neglected diseases of poverty. These programs would be highly cost effective and would significantly reduce the burden of morbidity and mortality of these diseases.

17 (13) Funding for research, preventive strate18 gies, and the development of treatments and diag19 nostic tests for neglected diseases of poverty in the
20 United States is limited.

#### 21 SEC. 3. SENSE OF CONGRESS.

It is the sense of Congress that there is a need to study the prevalence and incidence of neglected diseases of poverty in the United States, identify preventive methods to combat neglected diseases of poverty, conduct re-

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search that will lead to more treatments and diagnostic
 tests for neglected diseases of poverty, and supply health
 care providers, public health professionals, and affected in dividuals and communities with educational resources on
 neglected diseases of poverty.

### 6 SEC. 4. DEFINITION OF NEGLECTED DISEASES OF POV7 ERTY.

8 In this Act, the term "neglected diseases of poverty"
9 has the meaning given such term in section 399OO(e) of
10 the Public Health Service Act, as added by section 5.

## SEC. 5. PROGRAMS RELATING TO NEGLECTED DISEASES OF POVERTY.

13 Title III of the Public Health Service Act (42 U.S.C.
14 241 et seq.) is amended by adding at the end the fol15 lowing:

16 "PART W—PROGRAMS RELATING TO NEGLECTED
17 DISEASES OF POVERTY IN THE UNITED STATES
18 "SEC. 39900. INTERAGENCY TASK FORCE ON NEGLECTED
19 DISEASES OF POVERTY IN THE UNITED
20 STATES.

21 "(a) ESTABLISHMENT.—Not later than 180 days
22 after the date of enactment of the Study, Treat, Observe,
23 and Prevent Neglected Diseases of Poverty Act, the Sec24 retary shall establish an Interagency Task Force on Ne25 glected Diseases of Poverty in the United States to provide

advice and recommendations to the Secretary and Con gress to prevent, treat, and diagnose neglected diseases
 of poverty in the United States.
 "(b) MEMBERS.—The task force shall be comprised

5 of representatives of—

6 "(1) the Department of Health and Human 7 Services, including the Assistant Secretary for 8 Health and representatives from the Centers for 9 Disease Control and Prevention, the Food and Drug 10 Administration, the Health Resources and Services 11 Administration, the National Institutes of Health, 12 and the Biomedical Advanced Research and Devel-13 opment Authority;

14 "(2) the Department of State;

15 "(3) the United States Agency for International16 Development;

"(4) the Department of Agriculture;

18 "(5) the Department of Housing and Urban19 Development;

20 "(6) the Environmental Protection Agency; and
21 "(7) any other Federal agency that has juris22 diction over, or is affected by, neglected diseases of
23 poverty policies and projects, as determined by the
24 Secretary.

25 "(c) INITIAL REPORT.—

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1	"(1) IN GENERAL.—Not later than 180 days
2	after the date of enactment of the Study, Treat, Ob-
3	serve, and Prevent Neglected Diseases of Poverty
4	Act, the task force shall submit a report to the Sec-
5	retary based on a review of relevant literature to
6	identify gaps in efforts, and guide future efforts, to
7	prevent, identify, and treat neglected diseases of
8	poverty in the United States, particularly
9	toxocariasis, cysticercosis, Chagas disease, toxoplas-
10	mosis, trichomoniasis, and Dengue Fever. The re-
11	port shall include a summary of findings with re-
12	spect to—
13	"(A) estimated prevalence of neglected dis-
14	eases of poverty in the United States;
15	"(B) geographic distribution and major
16	distribution routes of neglected diseases of pov-
17	erty in the United States;
18	"(C) disparities with respect to the burden
19	of neglected diseases of poverty in the United
20	States;
21	"(D) risk factors for neglected diseases of
22	poverty in the United States;
23	"(E) existing tools for surveillance, preven-
24	tion, diagnosis, and treatment of neglected dis-
25	eases of poverty in the United States;

1	"(F) barriers to access to information and
2	tools for surveillance, prevention, diagnosis, and
3	treatment of neglected diseases of poverty in
4	the United States;
5	"(G) comorbidities associated with ne-
6	glected diseases of poverty in the United States;
7	"(H) awareness among health care pro-
8	viders and public health professionals regarding
9	neglected diseases of poverty in the United
10	States;
11	"(I) public awareness of neglected diseases
12	of poverty in the United States, particularly
13	among high-risk groups;
14	"(J) the economic burden of neglected dis-
15	eases of poverty in the United States; and
16	"(K) strategies and lessons learned from
17	the United States Agency for International De-
18	velopment Neglected Tropical Diseases Pro-
19	gram, particularly those that are most applica-
20	ble to efforts to prevent, diagnose, and treat ne-
21	glected diseases of poverty in the United States.
22	"(2) Consultation.—In developing the initial
23	report under paragraph (1), the task force shall con-
24	sult with appropriate external parties, including
25	States, local communities, scientists, researchers,

1	health care providers and public health professionals,
2	and national and international nongovermental orga-
3	nizations.
4	"(d) DUTIES.—The task force shall—
5	((1)) review and evaluate the current actions
6	and future plans of each applicable agency rep-
7	resented on the task force as described in subsection
8	(b) to prevent, diagnose, and treat neglected diseases
9	of poverty in the United States;
10	((2)) identify current and potential areas of
11	partnership and coordination between Federal agen-
12	cies and develop a unified implementation plan to
13	prevent, diagnose, and treat neglected diseases of
14	poverty in the United States;
15	"(3) make efforts to apply applicable strategies
16	and lessons learned from the United States Agency
17	for International Development Neglected Tropical
18	Diseases Program when developing the implementa-
19	tion plan under paragraph (2);
20	"(4) establish specific goals within and across
21	Federal agencies to prevent, diagnose, and treat ne-
22	glected diseases of poverty in the United States, in-
23	cluding metrics to assess progress towards reaching
24	those goals;

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"(5) coordinate plans to communicate research
 and relevant accomplishments across Federal agen cies and with States and local communities relating
 to the prevention, diagnosis, and treatment of ne glected diseases of poverty;

6 "(6) develop consensus guidelines for health 7 care providers and public health professionals for the 8 prevention, diagnosis, and treatment of toxocariasis, 9 cysticercosis, Chagas disease, toxoplasmosis, tricho-10 moniasis, Dengue Fever, and other neglected dis-11 eases of poverty;

12 "(7) biannually make recommendations to Con-13 gress on strategies for the development of affordable 14 tools to prevent, diagnose, and treat neglected dis-15 eases of poverty, including drugs, diagnostics, and 16 vaccines; and

17 "(8) in developing the guidelines and rec-18 ommendations under paragraphs (6) and (7), con-19 sult with external parties, including States, local 20 communities, scientists, researchers, health care pro-21 viders and public health professionals, national and 22 international nongovernmental organizations, and 23 centers of excellence with expertise in neglected dis-24 eases of poverty, including the centers of excellence 25 described in section 39900–5.

1	"(e) Definition of Neglected Diseases of Pov-
2	ERTY.—In this part, the term 'neglected diseases of pov-
3	erty'—
4	"(1) means chronic and disabling diseases that
5	are caused by parasites, bacteria, and other patho-
6	gens and that primarily impact people living in ex-
7	treme poverty; and
8	"(2) includes the following:
9	"(A) Chagas disease.
10	"(B) Cysticercosis.
11	"(C) Toxocariasis.
12	"(D) Toxoplasmosis.
13	"(E) Trichomoniasis.
14	"(F) Dengue Fever.
15	"(G) Other neglected tropical diseases, in-
16	cluding those defined by the World Health Or-
17	ganization, such as the following:
18	"(i) Buruli ulcer.
19	"(ii) Chikungunya.
20	"(iii) Dracunculiasis.
21	"(iv) Echinococcosis.
22	"(v) Foodborne trematodiases.
23	"(vi) Human African trypanosomiasis.
24	"(vii) Leishmaniases.
25	"(viii) Leprosy.

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1	"(ix) Lymphatic filariasis.
2	"(x) Mycetoma.
3	"(xi) Onchocerciasis.
4	"(xii) Rabies.
5	"(xiii) Schistosomiasis.
6	"(xiv) Soil-transmitted helminthiases.
7	"(xv) Taeniasis and
8	neurocysticercosis.
9	"(xvi) Trachoma.
10	"(xvii) Yaws.
11	"SEC. 39900-1. SURVEILLANCE REGARDING NEGLECTED
12	DISEASES OF POVERTY IN THE UNITED
12 13	DISEASES OF POVERTY IN THE UNITED STATES.
13	STATES.
13 14	<b>STATES.</b> "(a) IN GENERAL.—The Secretary, acting through
13 14 15	<b>STATES.</b> "(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Pre-
13 14 15 16	<b>STATES.</b> "(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Pre- vention, shall award grants to States to carry out activities
<ol> <li>13</li> <li>14</li> <li>15</li> <li>16</li> <li>17</li> </ol>	STATES. "(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Pre- vention, shall award grants to States to carry out activities relating to implementing a surveillance system to deter- mine the prevalence, incidence, and distribution of ne-
<ol> <li>13</li> <li>14</li> <li>15</li> <li>16</li> <li>17</li> <li>18</li> </ol>	STATES. "(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Pre- vention, shall award grants to States to carry out activities relating to implementing a surveillance system to deter- mine the prevalence, incidence, and distribution of ne-
<ol> <li>13</li> <li>14</li> <li>15</li> <li>16</li> <li>17</li> <li>18</li> <li>19</li> </ol>	STATES. "(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Pre- vention, shall award grants to States to carry out activities relating to implementing a surveillance system to deter- mine the prevalence, incidence, and distribution of ne- glected diseases of poverty, particularly those that most
<ol> <li>13</li> <li>14</li> <li>15</li> <li>16</li> <li>17</li> <li>18</li> <li>19</li> <li>20</li> </ol>	STATES. "(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Pre- vention, shall award grants to States to carry out activities relating to implementing a surveillance system to deter- mine the prevalence, incidence, and distribution of ne- glected diseases of poverty, particularly those that most impact individuals in the United States, including

23 (b) CONSIDERATIONS.—In awarding grants under
24 subsection (a), the Secretary shall use the findings in the
25 initial report of the Interagency Task Force on Neglected

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Diseases of Poverty in the United States under section
 399OO(c) to identify and prioritize geographic locations
 and communities that have the highest estimated preva lence of, or have populations at greatest risk of acquiring,
 neglected diseases of poverty, particularly those described
 in subsection (a).

# 7 "SEC. 39900-2. SUPPORT FOR INDIVIDUALS AT RISK FOR 8 NEGLECTED DISEASES OF POVERTY.

9 "(a) IN GENERAL.—The Secretary, acting through 10 the Director of the Centers for Disease Control and Pre-11 vention, shall award grants or cooperative agreements to 12 Federally qualified health centers to implement and ana-13 lyze the guidelines developed under section 399OO(d)(6).

14 "(b) INITIAL AWARDS.—The Secretary shall—

15 "(1) using the findings in the initial report of 16 the Interagency Task Force on Neglected Diseases 17 of Poverty in the United States under section 18 39900(c), identify the geographic locations in the 19 United States that have the highest estimated preva-20 lence of, or have populations at greatest risk of ac-21 quiring, neglected diseases of poverty, particularly 22 those that most impact individuals in the United 23 States, including toxocariasis, cysticercosis, Chagas 24 disease, toxoplasmosis, trichomoniasis, and Dengue 25 Fever; and

"(2) prioritize Federally qualified health centers
 located in such geographic locations in awarding ini tial grants or cooperative agreements under sub section (a).

5 "(c) DEFINITION OF FEDERALLY QUALIFIED
6 HEALTH CENTER.—In this section, the term 'Federally
7 qualified health center' has the meaning given the term
8 in section 1861(aa) of the Social Security Act.

9 "SEC. 39900-3. EDUCATION OF MEDICAL AND PUBLIC
10 HEALTH PERSONNEL AND THE PUBLIC RE11 GARDING NEGLECTED DISEASES OF POV12 ERTY IN THE UNITED STATES.

13 "The Secretary shall consult with the Assistant Sec-14 retary for Health, the Director of the Centers for Disease 15 Control and Prevention, and the Administrator of the 16 Health Resources and Services Administration, profes-17 sional organizations and societies, and such other public 18 health officials as may be necessary, including the centers 19 of excellence described in section 39900–5, to—

"(1) develop and implement educational programs to increase the awareness of health care providers and public health professionals with respect to
the risk factors, signs, and symptoms of neglected
diseases of poverty and strategies to prevent, diagnose, and treat such diseases; and

1 "(2) develop and implement educational pro-2 grams to increase the awareness of the public with 3 respect to the risk factors, signs, and symptoms of 4 neglected diseases of poverty and strategies to pre-5 vent such diseases.

### 6 "SEC. 39900-4. RESEARCH AND DEVELOPMENT OF NEW 7 DRUGS, VACCINES, AND DIAGNOSTICS.

8 "Consistent with the recommendations of the Inter-9 agency Task Force on Neglected Diseases of Poverty in 10 the United States established under section 39900, the 11 Secretary shall, directly or through awards of grants or 12 cooperative agreements to public or private entities, pro-13 vide for the conduct of research, investigations, experiments, demonstrations, and studies, including late-stage 14 15 and translational research, in the health sciences that are related to-16

17 "(1) the development of affordable therapeutics,
18 including vaccines, against neglected diseases of pov19 erty; and

20 "(2) the development of affordable medical
21 point-of-care diagnostics to detect neglected diseases
22 of poverty.

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## 1 "SEC. 39900-5. NEGLECTED DISEASES OF POVERTY CEN-2TERS OF EXCELLENCE.

3 "(a) ESTABLISHMENT.—The Secretary, acting jointly through the Director of the National Institutes of Health, 4 5 may enter into cooperative agreements with, and make grants to, public or private nonprofit entities to pay all 6 7 or part of the cost of planning, establishing, or strength-8 ening, and providing basic operating support for, one or 9 more centers of excellence for research into, training in, and development of diagnosis, prevention, control, and 10 11 treatment methods for neglected diseases of poverty in the 12 United States, including tools to support prevention.

13 "(b) ELIGIBILITY.—To be eligible to receive a cooper14 ative agreement or grant under subsection (a), an entity
15 shall have a demonstrated record of research on neglected
16 diseases of poverty.

17 "(c) COORDINATION.—The Secretary shall ensure
18 that activities under this section are coordinated with
19 similar activities of the Federal Government relating to
20 neglected diseases of poverty, including the task force es21 tablished under section 39900.

"(d) USE OF FUNDS.—A cooperative agreement or
grant awarded under subsection (a) may be used for—
"(1) staffing, administrative, and other basic
operating costs, including such patient care costs as
are required for research;

1	"(2) clinical training, including training for al-
2	lied health professionals, continuing education for
3	health professionals and allied health professions
4	personnel, and information programs for the public
5	with respect to neglected diseases of poverty;
6	"(3) research and development programs, in-
7	cluding the end-to-end research and development of
8	new treatments, diagnostics, and vaccines;
9	"(4) epidemiological surveillance and trans-
10	mission studies capabilities; and
11	"(5) health education programs to raise aware-
12	ness and reduce stigma of neglected diseases of pov-
13	erty among high-risk populations.
14	"(e) Period of Support; Additional Periods.—
15	"(1) IN GENERAL.—A cooperative agreement or
16	grant under this section may be provided for a pe-
17	riod of not more than 5 years.
18	"(2) EXTENSIONS.—The period specified in
19	paragraph (1) may be extended by the Secretary for
20	additional periods of not more than 5 years if—
21	"(A) the operations of the center of excel-
22	lence involved have been reviewed by an appro-
23	priate technical and scientific peer review
24	group; and

"(B) such group has recommended to the
 Secretary that such period be extended.

### 3 "SEC. 39900-6. AUTHORIZATION OF APPROPRIATIONS.

4 "To carry out this part, there are authorized to be
5 appropriated such sums as may be necessary for fiscal
6 year 2021 and each fiscal year thereafter.".