

116TH CONGRESS
1ST SESSION

H. R. 826

To facilitate effective research on and treatment of neglected tropical diseases, including Ebola, through coordinated domestic and international efforts.

IN THE HOUSE OF REPRESENTATIVES

JANUARY 28, 2019

Mr. SMITH of New Jersey (for himself, Ms. BASS, and Mr. MEEKS) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committees on Foreign Affairs, and Financial Services, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To facilitate effective research on and treatment of neglected tropical diseases, including Ebola, through coordinated domestic and international efforts.

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 “End Neglected Trop-
5 ical Diseases Act”.

6 **SEC. 2. TABLE OF CONTENTS.**

7 The table of contents of this Act is as follows:

Sec. 1. Short title.

- Sec. 2. Table of contents.
- Sec. 3. Statement of policy.
- Sec. 4. Findings.
- Sec. 5. Definition.
- Sec. 6. Rule of construction.

TITLE I—FOREIGN AFFAIRS

- Sec. 101. Expansion of United States Agency for International Development's Neglected Tropical Diseases Program.
- Sec. 102. Actions by Department of State.
- Sec. 103. Multilateral development and health institutions.

TITLE II—DEPARTMENT OF HEALTH AND HUMAN SERVICES

- Sec. 201. Promoting efforts through interagency working groups and international forums.
- Sec. 202. Report on neglected tropical diseases in the United States.
- Sec. 203. Centers of excellence.
- Sec. 204. Panel on worm infection solutions.

1 **SEC. 3. STATEMENT OF POLICY.**

2 It is the policy of the United States to support a
 3 broad range of implementation and research and develop-
 4 ment activities that work toward the achievement of cost-
 5 effective and sustainable treatment, control and, where
 6 possible, elimination of neglected tropical diseases, includ-
 7 ing Ebola, for the economic and social well-being for all
 8 people.

9 **SEC. 4. FINDINGS.**

10 Congress finds the following:

- 11 (1) The World Health Organization (WHO) has
- 12 identified 17 neglected tropical diseases (NTDs).
- 13 Approximately two billion people—almost one-third
- 14 of the world's population—are at risk of contracting
- 15 an NTD, and more than 1.4 billion people are cur-
- 16 rently afflicted with one or more NTDs.

1 (2) In 2013, WHO adopted a comprehensive
2 resolution on NTDs recognizing that increased na-
3 tional and international investments in prevention
4 and control of neglected tropical diseases have suc-
5 ceeded in improving health and social well-being in
6 many countries.

7 (3) NTDs have an enormous impact in terms of
8 disease burden and quality of life. NTDs cause the
9 loss of up to 534,000 lives and 57 million disability-
10 adjusted life years each year. NTDs surpass both
11 malaria and tuberculosis in causing greater loss of
12 life-years to disability and premature death. Many
13 NTDs cause disfigurement and disability, leading to
14 stigma, social discrimination, and societal marginali-
15 zation.

16 (4) NTDs create an economic burden of billions
17 of dollars through the loss of productivity and high
18 costs of health care required for treatment. People
19 afflicted by NTDs are less productive than their
20 healthy counterparts. NTDs jeopardize the ability of
21 people to attend work and school, or to produce at
22 full capacity. For example, controlling one NTD,
23 hookworm, in children can result in a 43-percent in-
24 crease in future wage earnings.

1 (5) The social, economic, and health burden of
2 NTDs falls primarily on low- and middle-income
3 countries, where access to safe water, sanitation,
4 and health care is limited. At least 100 countries
5 face two endemic NTD burdens, and 30 countries
6 carry six or more endemic NTDs.

7 (6) NTDs are not confined to the developing
8 world, however. Several NTD outbreaks have been
9 reported in the United States and other developed
10 countries, especially among the poor. In the United
11 States, NTDs disproportionately affect people living
12 in poverty, and especially minorities, including up to
13 2.8 million African Americans with toxocariasis and
14 300,000 or more people, mostly Hispanic Americans,
15 with Chagas disease.

16 (7) In 2014, an outbreak of Ebola Virus Dis-
17 eases (Ebola) caused a pandemic that infected more
18 than 20,000 people, including more than 8,000
19 deaths. Although not listed as an NTD by the World
20 Health Organization, Ebola shares the same charac-
21 teristics as other NTDs by affecting people living
22 “under conditions of poverty” and is “concentrated
23 almost exclusively in impoverished populations in the
24 developing world”. Even when the disease had
25 spread to the United States and other developed

1 countries, it was contained and controlled by the
2 well-equipped health systems in those areas.

3 (8) Many NTDs can be controlled, prevented,
4 and even eliminated using low-cost, effective, and
5 feasible solutions. Understanding the economic bur-
6 den of NTDs on productivity and health care costs
7 can help to assure governments and donors that the
8 resources directed toward NTDs represent a good
9 investment.

10 (9) Research and development efforts are imme-
11 diately needed for all NTDs, especially those for
12 which limited or no treatment currently exists.

13 (10) Critical to developing robust NTD control
14 strategies are epidemiological data that identify at-
15 risk populations, ensure appropriate treatment fre-
16 quency, and inform decisions about when treatment
17 can be reduced or stopped.

18 (11) Of the 14 most common NTDs, roughly
19 80 percent of infections are caused by soil-trans-
20 mitted helminths (STH) and schistosomiasis. STH
21 are a group of three parasitic worms (roundworms,
22 whipworms, and hookworms) that afflict more than
23 one billion people worldwide, including 600 million
24 school-age children, of whom more than 300 million
25 suffer from severe morbidity. Schistosomiasis is an-

1 other helminth infection affecting at least 200 mil-
2 lion people in developing countries, but some esti-
3 mates indicate that the true number of people af-
4 fected may be double or even triple that number.

5 (12) The main health problems caused by STH
6 are related to their negative effect on childhood nu-
7 tritional status, which can cause stunting and wast-
8 ing. For example, STH infection may lead to ane-
9 mia, malabsorption of nutrients, loss of appetite,
10 nausea, abdominal pain, diarrhea, and reduced food
11 intake. When such health problems are experienced
12 in early childhood, a peak growth and development
13 period, the mental and physical damage—and loss of
14 future productivity and wage-earning potential—will
15 likely be irreversible. Schistosomiasis causes end-
16 organ damage to the urinary tract, female genital
17 tract, liver and intestines. It also results in chronic
18 health conditions in children.

19 (13) STH and schistosomiasis are also particu-
20 larly detrimental to the health of women of repro-
21 ductive age and pregnant women. Their underlying
22 poor iron status makes these women most suscep-
23 tible to developing anemia. Iron deficiency anemia
24 resulting from hookworm infection during pregnancy
25 has been linked to poor pregnancy outcomes such as

1 prematurity, low birth weight, and impaired lacta-
2 tion. Female genital schistosmiasis may be one of
3 the most common gynecologic conditions in Africa
4 leading to genital pain, itching, and bleeding and
5 markedly increased susceptibility to HIV/AIDS.

6 (14) Fortunately, there is a simple, cost-effec-
7 tive solution to STH and schistosomiasis infections:
8 single-dose deworming pills that can be safely ad-
9 ministered once or twice annually to those at risk.
10 Pharmaceutical companies have committed to donate
11 the drugs needed to treat all at-risk, school-age chil-
12 dren in developing countries. Regular administration
13 of deworming pills reduces morbidity associated with
14 STH and schistosomiasis infections by reducing
15 prevalence and transmission rates.

16 (15) Improved access to water, sanitation, and
17 hygiene (WASH) can also reduce the transmission of
18 NTDs, particularly intestinal worms.

19 (16) The benefits of deworming are immediate
20 and enduring. A rigorous randomized controlled trial
21 has shown school-based deworming treatment to re-
22 duce school absenteeism by 25 percent. School-based
23 deworming also benefits young siblings and other
24 children who live nearby but are too young to be

1 treated, leading to large cognitive improvements
2 equivalent to half a year of schooling.

3 **SEC. 5. DEFINITION.**

4 In this Act, the term “neglected tropical diseases” or
5 “NTDs”—

6 (1) means infections caused by pathogens, in-
7 cluding viruses, bacteria, protozoa, and helminths
8 that disproportionately impact individuals living in
9 extreme poverty, especially in developing countries;
10 and

11 (2) includes—

12 (A) Buruli ulcer (*Mycobacterium Ulcerans*
13 infection);

14 (B) Chagas disease;

15 (C) dengue or severe dengue fever;

16 (D) dracunculiasis (Guinea worm disease);

17 (E) echinococcosis;

18 (F) foodborne trematodiasis;

19 (G) human African trypanosomiasis (sleep-
20 ing sickness);

21 (H) leishmaniasis;

22 (I) leprosy;

23 (J) lymphatic filariasis (elephantiasis);

24 (K) onchocerciasis (river blindness);

25 (L) rabies;

- 1 (M) schistosomiasis;
- 2 (N) soil-transmitted helminthiases (STH)
- 3 (round worm, whip worm, and hook worm);
- 4 (O) taeniasis/cysticercosis;
- 5 (P) trachoma; and
- 6 (Q) yaws (endemic treponematoses).

7 **SEC. 6. RULE OF CONSTRUCTION.**

8 Nothing in this Act shall be construed to increase au-
 9 thorizations of appropriations for the United States Agen-
 10 cy for International Development or authorizations of ap-
 11 propriations for the Department of Health and Human
 12 Services.

13 **TITLE I—FOREIGN AFFAIRS**

14 **SEC. 101. EXPANSION OF UNITED STATES AGENCY FOR**
 15 **INTERNATIONAL DEVELOPMENT'S NE-**
 16 **GLECTED TROPICAL DISEASES PROGRAM.**

17 (a) FINDINGS.—Congress finds the following:

18 (1) Since fiscal year 2006, the United States
 19 Government has been an essential leading partner in
 20 advancing control and elimination efforts for seven
 21 targeted neglected tropical diseases: lymphatic fila-
 22 riasis (elephantiasis), onchocerciasis (river blind-
 23 ness), schistosomiasis, soil-transmitted helminthiases
 24 (STH) (round worm, whip worm, and hook worm),
 25 and trachoma. Additional information suggests that

1 such efforts could also produce collateral benefits for
2 at least three other NTDs: foodborne trematodiasis,
3 scabies, and yaws (endemic treponematoses).

4 (2) The United States Agency for International
5 Development's (USAID) Neglected Tropical Dis-
6 eases Program has made important and substantial
7 contributions to the global fight to control and elimi-
8 nate the seven most common NTDs. Leveraging
9 more than \$6.7 billion in donated medicines, USAID
10 has supported the distribution of more than one bil-
11 lion treatments in 25 countries across Africa, Asia,
12 and Latin America and the Caribbean.

13 (3) United States Government leadership has
14 been instrumental in maintaining the global fight
15 against NTDs and is a partner in the London Dec-
16 laration on Neglected Tropical Diseases (2012),
17 which represents a new, coordinated international
18 push to accelerate progress toward eliminating or
19 controlling 10 neglected tropical diseases by 2020.

20 (4) USAID's Neglected Tropical Diseases Pro-
21 gram is a clear example of a successful public-pri-
22 vate partnership between the Government and the
23 private sector and should be judiciously expanded, as
24 practicable and appropriate.

1 (5) While many of the most common NTDs
2 have treatments that are safe, easy to use, and effec-
3 tive, treatment options for NTDs with the highest
4 death rates, including human African trypanosomia-
5 sis, visceral leishmaniasis, and Chagas disease, are
6 extremely limited.

7 (6) Since 2014, USAID’s Neglected Tropical
8 Diseases Program has been investing in gathering
9 research on treatment for certain NTDs to ensure
10 that promising new breakthrough medicines can be
11 rapidly evaluated, registered, and made available to
12 patients.

13 (b) SENSE OF CONGRESS.—It is the sense of Con-
14 gress that USAID’s Neglected Tropical Diseases Program
15 should—

16 (1) provide integrated drug treatment packages
17 to as many individuals suffering from NTDs or at
18 risk of acquiring NTDs as logistically feasible;

19 (2) better integrate control and treatment tools
20 and approaches for NTDs into complementary devel-
21 opment and global health programs by coordinating
22 across multiple sectors, including sectors relating to
23 HIV/AIDS, malaria, and other infectious diseases
24 and development sectors relating to education (in-
25 cluding primary and pre-primary education), food

1 and nutrition security, maternal and child health,
2 and water, sanitation, and hygiene (WASH), as
3 practicable and appropriate;

4 (3) establish low-cost, high-impact community
5 and school-based NTD programs to reach large at-
6 risk populations, including school-age children who
7 require treatments for NTDs, with integrated drug
8 treatment packages as feasible;

9 (4) for other NTDs, such as human African
10 trypanosomiasis (sleeping sickness), Chagas disease,
11 leishmaniasis, and dengue fever, engage in research
12 and development of new tools and approaches to
13 reach the goals relating to the elimination of NTDs
14 as set forth in the World Health Organization’s “Ac-
15 celerating Work to Overcome the Global Impact of
16 Neglected Tropical Diseases: A Roadmap for Imple-
17 mentation” (2012), as opportunities emerge and re-
18 sources allow; and

19 (5) monitor the research on and developments
20 in the prevention and treatment of other NTDs so
21 they can be incorporated into the program, as prac-
22 ticable and appropriate.

23 (c) PROGRAM PRIORITIES.—The Administrator of
24 USAID should incorporate the following priorities into
25 USAID’s Neglected Tropical Diseases Program:

1 (1) Planning for and conducting robust moni-
2 toring and evaluation of program investments in
3 order to accurately measure impact, identify and
4 share lessons learned, and inform future NTD con-
5 trol and elimination strategies.

6 (2) Coordinating program activities with
7 USAID development sectors, including development
8 sectors relating to education (including primary and
9 pre-primary education), food and nutrition security,
10 and water, sanitation, and hygiene (WASH), in
11 order to advance the goals of the London Declara-
12 tion on Neglected Tropical Diseases (2012).

13 (3) Including morbidity management in treat-
14 ment plans for high-burden NTDs.

15 (4) Incorporating NTDs that are recognized as
16 high-burden diseases in the Global Burden of Dis-
17 ease Study 2010 into the program as opportunities
18 emerge, to the extent practicable and appropriate.

19 (5) Continuing investments in research and de-
20 velopment for new tools, including diagnostics,
21 drugs, and vaccines, for NTDs to ensure that new
22 discoveries make it through the pipeline and become
23 available to individuals who need them most.

1 **SEC. 102. ACTIONS BY DEPARTMENT OF STATE.**

2 (a) OFFICE OF THE GLOBAL AIDS COORDINATOR.—

3 It is the sense of Congress that the Coordinator of United
4 States Government Activities to Combat HIV/AIDS Glob-
5 ally should fully consider evolving research on the impact
6 of neglected tropical diseases on efforts to control HIV/
7 AIDS when making future programming decisions, as nec-
8 essary and appropriate.

9 (b) GLOBAL PROGRAMMING.—

10 (1) IN GENERAL.—The Secretary of State
11 should encourage the Global Fund to take into con-
12 sideration evolving research on the impact of NTDs
13 on efforts to control HIV/AIDS when making pro-
14 gramming decisions, particularly with regard to fe-
15 male genital schistosomiasis, which has been re-
16 vealed as one of the most significant co-factors in
17 the AIDS epidemic in Africa, as necessary and ap-
18 propriate.

19 (2) GLOBAL FUND.—In this subsection, the
20 term “Global Fund” means the public-private part-
21 nership known as the Global Fund to Fight AIDS,
22 Tuberculosis and Malaria established pursuant to
23 Article 80 of the Swiss Civil Code.

24 (c) G-20 COUNTRIES.—The Secretary of State, act-
25 ing through the Office of Global Health Diplomacy, should
26 encourage G-20 countries, particularly Argentina, Brazil,

1 China, India, Indonesia, Mexico, the Republic of Korea,
2 Saudi Arabia, and South Africa, to significantly increase
3 their role in the control and elimination of NTDs.

4 **SEC. 103. MULTILATERAL DEVELOPMENT AND HEALTH IN-**
5 **STITUTIONS.**

6 (a) CONGRESSIONAL FINDING.—Congress finds that
7 the treatment of high burden neglected tropical diseases,
8 including community and school-based deworming pro-
9 grams, can be a highly cost-effective education interven-
10 tion and schools can serve as an effective delivery mecha-
11 nism for reaching large numbers of children with safe
12 treatment for soil-transmitted helminthiases (STH)
13 (round worm, whip worm, and hook worm) in particular.

14 (b) UNITED NATIONS.—The President should direct
15 the United States permanent representative to the United
16 Nations to use the voice, vote, and influence of the United
17 States to urge the World Health Organization and the
18 United Nations Development Programme to take the ac-
19 tions described in subsection (d).

20 (c) WORLD BANK INSTITUTE.—The President shall
21 direct the United States Executive Director at the Inter-
22 national Bank for Reconstruction and Development to use
23 the voice, vote, and influence of the United States to urge
24 the World Bank Institute to take the actions described
25 in subsection (d).

1 (d) ACTIONS DESCRIBED.—The actions described in
2 this subsection are the following:

3 (1) Ensure the dissemination of best practices
4 and programming on NTDs to governments and
5 make data accessible to practitioners in an open and
6 timely fashion.

7 (2) Highlight impacts of community and school-
8 based deworming programs on children’s health and
9 education, emphasizing the cost-effectiveness of such
10 programs.

11 (3) Encourage governments to implement
12 deworming campaigns at the national level.

13 (4) Designate a portion of grant funds of the
14 institutions to deworming initiatives and cross-sec-
15 toral collaboration with water and sanitation and hy-
16 giene efforts and nutrition or education program-
17 ming.

18 (5) Encourage accurate monitoring and evalua-
19 tion of NTD programs, including deworming pro-
20 grams.

21 (6) Engage governments in cross-border initia-
22 tives for the treatment, control, prevention, and
23 elimination of NTDs, and assist in developing
24 transnational agreements, when necessary.

1 **TITLE II—DEPARTMENT OF**
2 **HEALTH AND HUMAN SERVICES**

3 **SEC. 201. PROMOTING EFFORTS THROUGH INTERAGENCY**
4 **WORKING GROUPS AND INTERNATIONAL FO-**
5 **RUMS.**

6 The Secretary of Health and Human Services shall
7 continue to promote the need for robust programs and ac-
8 tivities to diagnose, prevent, control, and treat neglected
9 tropical diseases—

10 (1) through interagency working groups on
11 health; and

12 (2) through relevant international forums on
13 behalf of the United States, including the post-2015
14 United Nations development agenda.

15 **SEC. 202. REPORT ON NEGLECTED TROPICAL DISEASES IN**
16 **THE UNITED STATES.**

17 (a) IN GENERAL.—Not later than 12 months after
18 the date of enactment of this Act, the Secretary of Health
19 and Human Services, acting through relevant agencies of
20 the Department of Health and Human Services, shall sub-
21 mit to the Congress a report on neglected tropical diseases
22 in the United States.

23 (b) CONTENTS.—The report required by this section
24 shall—

1 (1) assess the epidemiology of, impact of, and
 2 appropriate funding required to address, neglected
 3 tropical diseases in the United States; and

4 (2) include the information necessary—

5 (A) to guide future health policy with re-
 6 spect to such diseases;

7 (B) to accurately evaluate the current
 8 state of knowledge concerning such diseases;
 9 and

10 (C) to define gaps in such knowledge.

11 **SEC. 203. CENTERS OF EXCELLENCE.**

12 Part P of title III of the Public Health Service Act
 13 is amended by inserting after section 399V–6 of such Act
 14 (42 U.S.C. 280g–17) the following:

15 **“SEC. 399V-7. NEGLECTED TROPICAL DISEASE CENTERS OF**
 16 **EXCELLENCE.**

17 “(a) COOPERATIVE AGREEMENTS AND GRANTS.—

18 “(1) IN GENERAL.—The Secretary, acting
 19 through the Director of the Centers for Disease
 20 Control and Prevention, may enter into cooperative
 21 agreements with, and make grants to, public or pri-
 22 vate nonprofit entities to pay all or part of the cost
 23 of planning, establishing, or strengthening, and pro-
 24 viding basic operating support for, one or more cen-
 25 ters of excellence for research into, training in, and

1 development of diagnosis, prevention, control, and
2 treatment methods for neglected tropical diseases,
3 including tools to support elimination.

4 “(2) ELIGIBILITY.—To be eligible for a cooper-
5 ative agreement or grant under this section, an enti-
6 ty must—

7 “(A) have demonstrated expertise in re-
8 search on, and or the epidemiology and surveil-
9 lance of, major neglected tropical diseases that
10 are endemic to the United States, such as
11 Chagas disease, dengue, leishmaniasis, West
12 Nile virus, and helminth infections; and

13 “(B) participate in one or more not-for-
14 profit product development partnerships.

15 “(b) POLICIES.—A cooperative agreement or grant
16 under paragraph (1) shall be entered into or awarded in
17 accordance with established policies.

18 “(c) COORDINATION.—The Secretary shall ensure
19 that activities under this section are coordinated with
20 similar activities of the Department of Health and Human
21 Services relating to neglected tropical diseases.

22 “(d) USES OF FUNDS.—A cooperative agreement or
23 grant under subsection (a) may be used for—

1 “(1) staffing, administrative, and other basic
2 operating costs, including such patient care costs as
3 are required for research;

4 “(2) clinical training, including training for al-
5 lied health professionals, continuing education for
6 health professionals and allied health professions
7 personnel, and information programs for the public
8 with respect to neglected tropical diseases; and

9 “(3) research and development programs.

10 “(e) PERIOD OF SUPPORT; ADDITIONAL PERIODS.—

11 “(1) IN GENERAL.—Support of a center of ex-
12 cellence under this section may be for a period of
13 not more than 5 years.

14 “(2) EXTENSIONS.—The period specified in
15 paragraph (1) may be extended by the Secretary for
16 additional periods of not more than 5 years if—

17 “(A) the operations of the center of excel-
18 lence involved have been reviewed by an appro-
19 priate technical and scientific peer review
20 group; and

21 “(B) such group has recommended to the
22 Secretary that such period should be extended.

23 “(f) DEFINITIONS.—In this section:

1 “(1) The term ‘neglected tropical diseases’ has
2 the meaning given to that term in section 5 of the
3 End Neglected Tropical Diseases Act.

4 “(2) The term ‘product development partner-
5 ship’ means a partnership to bring together public
6 and private sector researchers to develop new, or im-
7 prove on current, global health tools, such as drugs,
8 diagnostics, insecticides, vaccines, and vector man-
9 agement strategies—

10 “(A) that are for neglected tropical dis-
11 eases, including Ebola; and

12 “(B) for which there is generally no profit-
13 able market.”.

14 **SEC. 204. PANEL ON WORM INFECTION SOLUTIONS.**

15 (a) **ESTABLISHMENT.**—The Secretary of Health and
16 Human Services shall establish a panel to conduct an eval-
17 uation of issues relating to worm infections, including po-
18 tential solutions such as deworming medicines (in this sec-
19 tion referred to as the “panel”).

20 (b) **STRATEGIES.**—The panel shall develop rec-
21 ommendations for strategies for solutions with respect
22 to—

- 23 (1) repeat infections;
24 (2) vector control;
25 (3) clean water solutions;

1 (4) identifying incentives to encourage basic re-
2 search for less toxic, more effective medicines; and

3 (5) improving the success and cost efficiency of
4 current programs in these areas, based on a thor-
5 ough scan of initiatives already underway in both
6 the public and private sectors.

7 (c) APPOINTMENT OF MEMBERS.—In addition to
8 representatives from the Centers for Disease Control and
9 Prevention and other relevant agencies working on ne-
10 glected tropical diseases, the Secretary of Health and
11 Human Services shall appoint as members of the panel
12 individuals from the public and private sectors who are
13 knowledgeable about or affected by worm infections, in-
14 cluding—

15 (1) at least 2 representatives of nongovern-
16 mental organizations;

17 (2) at least 2 representatives of private industry
18 involved in the development of de-worming medica-
19 tions;

20 (3) at least 2 representatives from academia;
21 and

22 (4) representatives of industries relating to
23 sanitation, clean water, and vector control.

24 (d) REPORT.—Not later than 1 year after the date
25 of the enactment of this Act, the panel shall submit to

1 Congress and the Secretary of Health and Human Serv-
2 ices a report on its findings and recommended strategies,
3 including recommendations for such administrative action
4 and legislation as the panel determines to be appropriate.

5 (e) TERMINATION.—The panel shall terminate not
6 later than 6 months after submitting the report required
7 by subsection (d).

○