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

IN THE HOUSE OF REPRESENTATIVES

March 7, 2017

Mr. Smith of New Jersey (for himself 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 Representatives of the United States of America in Congress assembled,

2 SECTION 1. SHORT TITLE.

3 This Act may be cited as the “End Neglected Tropical Diseases Act”.

4 SEC. 2. TABLE OF CONTENTS.

5 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. 203. Centers of excellence.
Sec. 204. Panel on worm infection solutions.

1 SEC. 3. STATEMENT OF POLICY.

It is the policy of the United States to support a broad range of implementation and research and development activities that work toward the achievement of cost-effective and sustainable treatment, control and, where possible, elimination of neglected tropical diseases, including Ebola, for the economic and social well-being for all people.

2 SEC. 4. FINDINGS.

Congress finds the following:

(1) The World Health Organization (WHO) has identified 17 neglected tropical diseases (NTDs).

Approximately two billion people—almost one-third of the world’s population—are at risk of contracting an NTD, and more than 1.4 billion people are currently afflicted with one or more NTDs.
(2) In 2013, WHO adopted a comprehensive resolution on NTDs recognizing that increased national and international investments in prevention and control of neglected tropical diseases have succeeded in improving health and social well-being in many countries.

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

(4) NTDs create an economic burden of billions of dollars through the loss of productivity and high costs of health care required for treatment. People afflicted by NTDs are less productive than their healthy counterparts. NTDs jeopardize the ability of people to attend work and school, or to produce at full capacity. For example, controlling one NTD, hookworm, in children can result in a 43-percent increase in future wage earnings.
(5) The social, economic, and health burden of NTDs falls primarily on low- and middle-income countries, where access to safe water, sanitation, and health care is limited. At least 100 countries face two endemic NTD burdens, and 30 countries carry six or more endemic NTDs.

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

(7) In 2014, an outbreak of Ebola Virus Diseases (Ebola) caused a pandemic that infected more than 20,000 people, including more than 8,000 deaths. Although not listed as an NTD by the World Health Organization, Ebola shares the same characteristics as other NTDs by affecting people living “under conditions of poverty” and is “concentrated almost exclusively in impoverished populations in the developing world”. Even when the disease had spread to the United States and other developed
countries, it was contained and controlled by the well-equipped health systems in those areas.

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

(9) Research and development efforts are immediately needed for all NTDs, especially those for which limited or no treatment currently exists.

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

(11) Of the 14 most common NTDs, roughly 80 percent of infections are caused by soil-transmitted helminths (STH) and schistosomiasis. STH are a group of three parasitic worms (roundworms, whipworms, and hookworms) that afflict more than one billion people worldwide, including 600 million school-age children, of whom more than 300 million suffer from severe morbidity. Schistosomiasis is an-
other helminth infection affecting at least 200 million people in developing countries, but some estimates indicate that the true number of people affected may be double or even triple that number.

(12) The main health problems caused by STH are related to their negative effect on childhood nutritional status, which can cause stunting and wasting. For example, STH infection may lead to anemia, malabsorption of nutrients, loss of appetite, nausea, abdominal pain, diarrhea, and reduced food intake. When such health problems are experienced in early childhood, a peak growth and development period, the mental and physical damage—and loss of future productivity and wage-earning potential—will likely be irreversible. Schistosomiasis causes end-organ damage to the urinary tract, female genital tract, liver and intestines. It also results in chronic health conditions in children.

(13) STH and schistosomiasis are also particularly detrimental to the health of women of reproductive age and pregnant women. Their underlying poor iron status makes these women most susceptible to developing anemia. Iron deficiency anemia resulting from hookworm infection during pregnancy has been linked to poor pregnancy outcomes such as
prematurity, low birth weight, and impaired lactation. Female genital schistosomiasis may be one of the most common gynecologic conditions in Africa leading to genital pain, itching, and bleeding and markedly increased susceptibility to HIV/AIDS.

(14) Fortunately, there is a simple, cost-effective solution to STH and schistosomiasis infections: single-dose deworming pills that can be safely administered once or twice annually to those at risk. Pharmaceutical companies have committed to donate the drugs needed to treat all at-risk, school-age children in developing countries. Regular administration of deworming pills reduces morbidity associated with STH and schistosomiasis infections by reducing prevalence and transmission rates.

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

(16) The benefits of deworming are immediate and enduring. A rigorous randomized controlled trial has shown school-based deworming treatment to reduce school absenteeism by 25 percent. School-based deworming also benefits young siblings and other children who live nearby but are too young to be
treated, leading to large cognitive improvements equivalent to half a year of schooling.

SEC. 5. DEFINITION.

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

(1) means infections caused by pathogens, including viruses, bacteria, protozoa, and helminths that disproportionately impact individuals living in extreme poverty, especially in developing countries; and

(2) includes—

(A) Buruli ulcer (Mycobacterium Ulcerans infection);

(B) Chagas disease;

(C) dengue or severe dengue fever;

(D) dracunculiasis (Guinea worm disease);

(E) echinococcosis;

(F) foodborne trematodiases;

(G) human African trypanosomiasis (sleeping sickness);

(H) leishmaniasis;

(I) leprosy;

(J) lymphatic filariasis (elephantiasis);

(K) onchoerciasis (river blindness);

(L) rabies;
(M) schistosomiasis;
(N) soil-transmitted helminthiases (STH) (round worm, whip worm, and hook worm);
(O) taeniasis/cysticercosis;
(P) trachoma; and
(Q) yaws (endemic treponematoses).

SEC. 6. RULE OF CONSTRUCTION.

Nothing in this Act shall be construed to increase authorizations of appropriations for the United States Agency for International Development or authorizations of appropriations for the Department of Health and Human Services.

TITLE I—FOREIGN AFFAIRS

SEC. 101. EXPANSION OF UNITED STATES AGENCY FOR INTERNATIONAL DEVELOPMENT’S NEGLECTED TROPICAL DISEASES PROGRAM.

(a) FINDINGS.—Congress finds the following:

(1) Since fiscal year 2006, the United States Government has been an essential leading partner in advancing control and elimination efforts for seven targeted neglected tropical diseases: lymphatic filariasis (elephantiasis), onchocerciasis (river blindness), schistosomiasis, soil-transmitted helminthiases (STH) (round worm, whip worm, and hook worm), and trachoma. Additional information suggests that
such efforts could also produce collateral benefits for at least three other NTDs: foodborne trematodiases, scabies, and yaws (endemic treponematoses).

(2) The United States Agency for International Development’s (USAID) Neglected Tropical Diseases Program has made important and substantial contributions to the global fight to control and eliminate the seven most common NTDs. Leveraging more than $6.7 billion in donated medicines, USAID has supported the distribution of more than one billion treatments in 25 countries across Africa, Asia, and Latin America and the Caribbean.

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

(4) USAID’s Neglected Tropical Diseases Program is a clear example of a successful public-private partnership between the Government and the private sector and should be judiciously expanded, as practicable and appropriate.
(5) While many of the most common NTDs have treatments that are safe, easy to use, and effective, treatment options for NTDs with the highest death rates, including human African trypanosomiasis, visceral leishmaniasis, and Chagas disease, are extremely limited.

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

(b) SENSE OF CONGRESS.—It is the sense of Congress that USAID’s Neglected Tropical Diseases Program should—

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

(2) better integrate control and treatment tools and approaches for NTDs into complementary development and global health programs by coordinating across multiple sectors, including sectors relating to HIV/AIDS, malaria, and other infectious diseases and development sectors relating to education (including primary and pre-primary education), food
and nutrition security, maternal and child health, and water, sanitation, and hygiene (WASH), as practicable and appropriate;

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

(4) for other NTDs, such as human African trypanosomiasis (sleeping sickness), Chagas disease, leishmaniasis, and dengue fever, engage in research and development of new tools and approaches to reach the goals relating to the elimination of NTDs as set forth in the World Health Organization’s “Accelerating Work to Overcome the Global Impact of Neglected Tropical Diseases: A Roadmap for Implementation” (2012), as opportunities emerge and resources allow; and

(5) monitor the research on and developments in the prevention and treatment of other NTDs so they can be incorporated into the program, as practicable and appropriate.

(e) Program Priorities.—The Administrator of USAID should incorporate the following priorities into USAID’s Neglected Tropical Diseases Program:
(1) Planning for and conducting robust monitoring and evaluation of program investments in order to accurately measure impact, identify and share lessons learned, and inform future NTD control and elimination strategies.

(2) Coordinating program activities with USAID development sectors, including development sectors relating to education (including primary and pre-primary education), food and nutrition security, and water, sanitation, and hygiene (WASH), in order to advance the goals of the London Declaration on Neglected Tropical Diseases (2012).

(3) Including morbidity management in treatment plans for high-burden NTDs.

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

(5) Continuing investments in research and development for new tools, including diagnostics, drugs, and vaccines, for NTDs to ensure that new discoveries make it through the pipeline and become available to individuals who need them most.
SEC. 102. ACTIONS BY DEPARTMENT OF STATE.

(a) Office of the Global AIDS Coordinator.—

It is the sense of Congress that the Coordinator of United States Government Activities to Combat HIV/AIDS Globally should fully consider evolving research on the impact of neglected tropical diseases on efforts to control HIV/AIDS when making future programming decisions, as necessary and appropriate.

(b) Global Programming.—

(1) In general.—The Secretary of State should encourage the Global Fund to take into consideration evolving research on the impact of NTDs on efforts to control HIV/AIDS when making programming decisions, particularly with regard to female genital schistosomiasis, which has been revealed as one of the most significant co-factors in the AIDS epidemic in Africa, as necessary and appropriate.

(2) Global Fund.—In this subsection, the term “Global Fund” means the public-private partnership known as the Global Fund to Fight AIDS, Tuberculosis and Malaria established pursuant to Article 80 of the Swiss Civil Code.

(c) G–20 Countries.—The Secretary of State, acting through the Office of Global Health Diplomacy, should encourage G–20 countries, particularly Argentina, Brazil,
China, India, Indonesia, Mexico, the Republic of Korea, Saudi Arabia, and South Africa, to significantly increase their role in the control and elimination of NTDs.

SEC. 103. MULTILATERAL DEVELOPMENT AND HEALTH INSTITUTIONS.

(a) CONGRESSIONAL FINDING.—Congress finds that the treatment of high burden neglected tropical diseases, including community and school-based deworming programs, can be a highly cost-effective education intervention and schools can serve as an effective delivery mechanism for reaching large numbers of children with safe treatment for soil-transmitted helminthiases (STH) (round worm, whip worm, and hook worm) in particular.

(b) UNITED NATIONS.—The President should direct the United States permanent representative to the United Nations to use the voice, vote, and influence of the United States to urge the World Health Organization and the United Nations Development Programme to take the actions described in subsection (d).

(c) WORLD BANK INSTITUTE.—The President shall direct the United States Executive Director at the International Bank for Reconstruction and Development to use the voice, vote, and influence of the United States to urge the World Bank Institute to take the actions described in subsection (d).
(d) ACTIONS DESCRIBED.—The actions described in this subsection are the following:

1. Ensure the dissemination of best practices and programming on NTDs to governments and make data accessible to practitioners in an open and timely fashion.

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

3. Encourage governments to implement deworming campaigns at the national level.

4. Designate a portion of grant funds of the institutions to deworming initiatives and cross-sectoral collaboration with water and sanitation and hygiene efforts and nutrition or education programming.

5. Encourage accurate monitoring and evaluation of NTD programs, including deworming programs.

6. Engage governments in cross-border initiatives for the treatment, control, prevention, and elimination of NTDs, and assist in developing transnational agreements, when necessary.
TITLE II—DEPARTMENT OF
HEALTH AND HUMAN SERVICES

SEC. 201. PROMOTING EFFORTS THROUGH INTERAGENCY
WORKING GROUPS AND INTERNATIONAL FORUMS.

The Secretary of Health and Human Services shall continue to promote the need for robust programs and activities to diagnose, prevent, control, and treat neglected tropical diseases—

(1) through interagency working groups on health; and

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

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

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

(b) CONTENTS.—The report required by this section shall—
18

(1) assess the epidemiology of, impact of, and
appropriate funding required to address, neglected
tropical diseases in the United States; and
(2) include the information necessary—
(A) to guide future health policy with re-
spect to such diseases;
(B) to accurately evaluate the current
state of knowledge concerning such diseases;
and
(C) to define gaps in such knowledge.

SEC. 203. CENTERS OF EXCELLENCE.

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

“SEC. 399V–7. NEGLECTED TROPICAL DISEASE CENTERS OF
EXCELLENCE.

“(a) COOPERATIVE AGREEMENTS AND GRANTS.—
“(1) IN GENERAL.—The Secretary, acting
through the Director of the Centers for Disease
Control and Prevention, may enter into cooperative
agreements with, and make grants to, public or pri-
"
development of diagnosis, prevention, control, and
treatment methods for neglected tropical diseases,
including tools to support elimination.

“(2) ELIGIBILITY.—To be eligible for a coopera-
tive agreement or grant under this section, an enti-
ty must—

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

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

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

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

“(d) USES OF FUNDS.—A cooperative agreement or
grant 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;

“(2) clinical training, including training for allied health professionals, continuing education for health professionals and allied health professions personnel, and information programs for the public with respect to neglected tropical diseases; and

“(3) research and development programs.

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

“(1) IN GENERAL.—Support of a center of excellence under this section may be for a period of not more than 5 years.

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

“(A) the operations of the center of excellence involved have been reviewed by an appropriate technical and scientific peer review group; and

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

“(f) DEFINITIONS.—In this section:
“(1) The term ‘neglected tropical diseases’ has the meaning given to that term in section 5 of the End Neglected Tropical Diseases Act.

“(2) The term ‘product development partnership’ means a partnership to bring together public and private sector researchers to develop new, or improve on current, global health tools, such as drugs, diagnostics, insecticides, vaccines, and vector management strategies—

“(A) that are for neglected tropical diseases, including Ebola; and

“(B) for which there is generally no profitable market.”.

SEC. 204. PANEL ON WORM INFECTION SOLUTIONS.

(a) Establishment.—The Secretary of Health and Human Services shall establish a panel to conduct an evaluation of issues relating to worm infections, including potential solutions such as deworming medicines (in this section referred to as the “panel”).

(b) Strategies.—The panel shall develop recommendations for strategies for solutions with respect to—

(1) repeat infections;

(2) vector control;

(3) clean water solutions;
(4) identifying incentives to encourage basic research for less toxic, more effective medicines; and

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

(e) APPOINTMENT OF MEMBERS.—In addition to representatives from the Centers for Disease Control and Prevention and other relevant agencies working on neglected tropical diseases, the Secretary of Health and Human Services shall appoint as members of the panel individuals from the public and private sectors who are knowledgeable about or affected by worm infections, including—

(1) at least 2 representatives of nongovernmental organizations;

(2) at least 2 representatives of private industry involved in the development of de-worming medications;

(3) at least 2 representatives from academia; and

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

(d) REPORT.—Not later than 1 year after the date of the enactment of this Act, the panel shall submit to
Congress and the Secretary of Health and Human Services a report on its findings and recommended strategies, including recommendations for such administrative action and legislation as the panel determines to be appropriate.

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