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“Addressing the Neglected Diseases Treatment Gap”

*Excerpts of Remarks by Chairman Chris Smith
Subcommittee on Africa, Global Health, Global Human Rights, and Int'l Orgs.
2200 Rayburn HOB
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Good afternoon. Today's hearing will examine the neglected diseases that affect a relatively small but significant number of children around the world.

These diseases are not only debilitating for their victims but too often fatal when untreated. Such diseases largely impact poor people in poor countries. They are not only small in numbers, but they are unable to pay market prices for treatments and are unlikely to lead social movements to force action on their diseases. That means that research on detection, vaccines and drug treatment for their ailments does not receive the priority that diseases such as HIV-AIDS, often seen in pandemic levels, are given.

The World Health Organization has identified 17 neglected tropical diseases or NTDs. The list ranges from chagas to rabies to leprosy to dengue fever. However, there are others not on this list of 17 diseases that also receive less attention. These include such diseases as polio and smallpox, which have largely been eliminated from the planet, and fatal, fortunately rare NTDs such as kuru and ebola.

This hearing will consider the current U.S. government handling of these neglected diseases to determine what more can or should be done to address this situation. Current U.S. law favors research on those diseases threatening the American homeland, but in today's world, diseases can cross borders as easily as those affected by them or the products imported into the United States. For example, chagas is most prevalent in Latin America, but it has been identified in patients in Texas, and cases of dengue fever have recently been reported in Florida. We cannot afford to assume that what may seem to be exotic diseases only happen to people in other countries. Ten years ago, West Nile Virus, another NTD, was not seen in the United States or anywhere else outside the East African nation of Uganda, but in less than a decade, it has spread across this country and much of the rest of the world. Last year, 286 people died from West Nile

virus in the United States alone. As recently as the mid-1990s, this disease was seen only sporadically and was considered a minor risk for human beings.

Generally, NTDs affect the health of the poor in developing countries where access to clean water, sanitation, and health care is limited. Roughly 2 billion people are being treated for at least one NTD, although most individuals are infected with several NTDs at once. Several NTDs are difficult to control by drug treatment alone because of their complicated transmission cycles that involve non-human-carriers such as insects. Furthermore, some of the drugs have significant side effects (including death) and cannot be used by young children or pregnant women.

A study done in 2001 found that research and development of drugs to treat infectious diseases had ground to a near-standstill. From 1975 to 1999, the report stated, 1,393 new drugs were brought to the market globally, but only 16, or 1.1 percent, were for tropical diseases (including malaria) and even tuberculosis, although these diseases represented 12% of the global disease burden. A 2012 update of that study found that the gap between the percentage of research and development on NTDs and their percentage of the global disease burden had narrowed, but there is still a long way to go to reach an adequate balance. Of the 756 new drugs approved between 2000 and 2011, 29 (or 3.8 percent) were for neglected diseases, although the global burden of such diseases was estimated at 10.5 percent. Of these, only four were new chemical creations, three of which were for malaria, but none for tuberculosis or neglected tropical diseases.

It is unprofitable for companies to create treatments for diseases with few victims and no certain way to recover research and development costs. Our heart goes out to those who suffer from these neglected diseases, and we want our government to speed up research and development in cooperation with universities and private companies. However, research and development take time and effort and costs money that private companies cannot easily justify to their stockholders, including many of us, without incentives. We are here today to consider such incentives and look at the system in place to forge successful efforts to deal with NTDs.

We have with us representatives from the National Institutes of Health, which was established to understand, treat and ultimately prevent the many infectious, immunologic and allergic diseases that threaten millions of human lives. Their government partner in the system for developing solutions to the problem of NTDs and other diseases is the Food and Drug Administration, which, among other responsibilities, is charged with protecting and promoting public health through the regulation and supervision of prescription and over-the-counter pharmaceutical medications, vaccines and biopharmaceuticals.

Also joining us today are representatives from a network specializing in providing medicines at the lowest possible cost to those suffering from NTDs, a major pharmaceutical company that develops new drugs for the treatment of diseases rare and otherwise, and a new organization seeking to extend the benefits of proven interventions to improve the lives of the poor in developing countries. If a solution to the gap between existing research and development and successful strategies to meet the challenges of NTDs is to be found, it will take the collaboration of the organizations represented here today, as well as numerous others.

What yesterday was a disease affecting a tiny population in a remote area of the world can tomorrow become an unexpected, global epidemic. We must be better prepared to deal with new challenges to public health.