

March 10, 2020

**Subcommittee on State, Foreign Operations, and Related Programs  
U.S. Agency for International Development**

**Tuberculosis**

**Recommendation: \$400 million**

**Kate O'Brien**

**We are TB**

On behalf of We Are TB and tuberculosis patients and survivors across the USA and around the world, I'm honored to provide this testimony to the House Committee on Appropriations, Subcommittee on State, Foreign Operations, and Related Programs. I am very proud of the steps my country has recently taken to combat tuberculosis (TB) as it becomes increasingly drug resistant. I ask you to please consider increasing funding for USAID's tuberculosis program to \$400 million in Fiscal year 2021 and fully implement the *US National Action Plan to Combat MDR-TB*, for the safety and security of our families. I wish to share with you the way my own family was impacted by tuberculosis, the number one infectious disease killer in the world. What happened to me happens to 10 million people around the world every year, with resulting suffering and death, plus they and their families are often pushed into poverty by job loss and costs related to diagnosis and treatment.

In September 2014 I was the happiest I had ever been. I was living in a cool neighborhood in Brooklyn, working two great freelance gigs, happily married with a beautiful little boy and I had just learned I was pregnant again. Everything was perfect, but I had problems enjoying it. I just couldn't shake this terrible cold! I had night sweats, I coughed up blood. I should have been gaining weight, but I wasn't. It was falling off me as I had no desire to eat anything. I tried to choke things down for the sake of my baby but the coughing made my throat raw and eventually it was very difficult to swallow.

I was going to all sorts of doctors but no one could tell me what was wrong. Not my primary care physician, not my OB/GYN, not a hematologist, not an Ear Nose, Throat doctor. Sicker and sicker, wasting away at 90 pounds and dehydrated, after 5 months of misery I was finally hospitalized in January 2015. I had no idea I would be there until April. I told my job I'd be back in a week, the longest. I didn't say goodbye to my son.

It took two weeks, a failed intubation and a trip to the ICU for me to get a chest x-ray and the almost immediate diagnosis of active pulmonary tuberculosis. I was immediately quarantined and remained in isolation for the many weeks that followed. Suddenly imprisoned, I went from being a boring stroller-pushing mom to threatening the health of New York City. My family,

friends and all of my co-workers were screened and the results given to the city department of health. I didn't like isolation, I felt humiliated by the invasiveness of the contact investigation, but the only thing that really mattered to me was my baby. No doctor could tell me what the results of this disease, my malnourishment or the antibiotics would be on my pregnancy. I loved my baby. My husband and parents visited me almost every day but my baby was the only one with me during all those lonely hours.

I took antibiotics for a year in total, but in April I was no longer infectious, and I could be released from the hospital and finally see my son. I delivered a healthy baby boy later that month. I lost my freelance jobs and we had to leave Brooklyn and live with my parents for over a year to pay off my hospital bills. The hospital bills were well over half a million dollars. We had insurance, and only were responsible for a fraction of that, but it was still a huge debt we did not anticipate or plan for before I was hospitalized. Despite this, it was so easy to see that I was still very lucky when I looked at my baby in my skeletal arms. TB is the world's third leading cause of death among women of reproductive age, and over 1 million children contracted tuberculosis in 2018.

During the year that followed, by medication was brought to me daily by a state health worker, who watched me take it. Tuberculosis is *airborne* infectious, and when treatment is not completed fully the bacteria can become resistant. Each tuberculosis patient must be given individualized attention and their families - sometimes entire communities must be screened. One can imagine the labor costs that would be incurred by a public health department if we had more TB cases in this country, and why it is hard to monitor tuberculosis patients and ensure they complete long treatment regimens in countries with less resources and many more cases. The antibiotics used to treat tuberculosis caused me to have nausea, diarrhea, liver problems and other unpleasant side effects. TB drugs, especially the ones used to treat drug-resistant TB - can cause neuropathy and deafness. People with TB must fully understand the importance of completing their full treatment even if they feel terrible while taking it, and that communication takes time and care.

On September 26, 2018, the United Nations held the first-ever High-Level Meeting on TB, where 120 countries, including the U.S., signed a Political Declaration committing to accelerating the TB response, including increasing funding for TB control programs and research and development efforts. Awareness and action to combat TB have increased, but more global leadership and prioritization is needed.

USAID's TB program has done masterful work across the globe aimed at getting countries the technical support they need to quickly find people with TB and ensure proper diagnosis and treatment. The U.S. Agency for International Development (USAID) is the largest bilateral donor supporting global TB prevention and control in 23 countries, including Afghanistan, India,

and Ethiopia. USAID supports the implementation of the World Health Organization END TB strategy in priority countries and the goals and targets set forth in the Global Plan. Through its support for the Stop TB Partnership, USAID is backing awareness-raising and advocacy by people like me, survivors of TB who can raise the urgency of the issue in personal terms. USAID also has great success in research and development of new, shorter, treatment regimens and improved diagnostics. I now do TB advocacy, and each year I feel I become more and more aware of the incredible importance of this agency. I wish to express my extreme gratitude for the funding increases USAID's TB program has received in 2018 and 2019. I ask you to please consider an additional increase to \$400 million for USAID's TB program in fiscal year 2021, so that we can finally achieve TB elimination, while also supporting long overdue increases for CDC global and domestic TB programs through the Labor, Health and Human services appropriations bill. There are several promising TB vaccine candidates out there, the end of this illness is truly possible, but backing for both TB implementation and research are crucial.

As selected representatives, I need you to remember the most vulnerable in your constituency - the very young and old, the poor, the sick - are ones most vulnerable to tuberculosis. I thank you for thinking of them, and of my family during this period in your busy day today.

Sincerely yours,

Kate O'Brien

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