

Ask Your Senator to Lead on Tuberculosis

Since 2015, tuberculosis (TB) has been *the leading infectious disease killer in the world*, surpassing HIV/AIDS. Far from being a disease of the past, TB sickens 10.4 million people and kills 1.7 million people each year.¹ An easily spread, airborne pathogen, TB disproportionately affects people in poor and vulnerable communities and drives many people deeper into poverty.

TB is preventable, treatable, and in almost all cases, it is curable. Yet the world is failing to diagnose and treat **40 percent** of people who become sick with TB each year.² With new, better data showing country-by-country where these people are, the world has an opportunity to find these missing people, cure their TB, and reduce the spread of this killer.

Who is TB impacting?

- The World Health Organization estimates that one million children develop TB every year and that 90 percent of children with TB go untreated.³ We cannot reach the goal of ending preventable child and maternal deaths if we fail to also address TB.
- An estimated 1.78 million adolescents develop TB every year⁴, and in many countries, schools are known to be TB transmission hot spots.
- Pregnant women are especially vulnerable to TB – in fact, a woman’s chance of developing the disease doubles during pregnancy.⁵
- Stigma, shame, and discrimination resulting from TB makes the epidemic much worse. In some settings women ill with TB are ostracized by their families and communities.
- TB is the leading killer of people living with HIV/AIDS. Of 10.4 million people who became ill with TB in 2016, one-in-ten live with HIV/AIDS.⁶ Failure to invest in TB threatens the substantial gains we have made on HIV/AIDS.



Opportunities: Worldwide Attention in 2018

In 2018 there are major new opportunities to accelerate progress in the fight against TB. Scientific innovations in diagnostics, treatment, and prevention are giving new hope. And the political will to address TB is on the rise as demonstrated by the first-ever UN High Level Meeting (UNHLM) on TB scheduled for September 26.⁸ The UNHLM is an opportunity for heads of state from around the world to make specific commitments to end the disease.

Challenges: Finding the Unreached and Drug-Resistant TB

TB deaths fell globally by 37 percent between 2000 and 2016.⁹ But, while there have been advances on TB, progress on reducing new cases of TB is at just 1.5 percent per year globally.¹⁰ The response to TB has been far too passive, jeopardizing the possibility of ending TB, and leaving

too many people suffering with and vulnerable to TB. We must find more people with TB, both active and latent forms, if we want to end this disease, but that will require more resources.

The longer we wait to act aggressively on TB, the greater the risk of spreading more deadly forms of TB. Approximately 600,000 people per year develop a form of TB that is resistant to multiple antibiotics, called multi-drug resistant TB (MDR-TB).¹² Once on treatment, a patient quickly becomes non-infectious, yet only 22 percent of patients with drug-resistant TB receive any treatment.¹³ An even worse form of drug-resistant TB called extensively drug-resistant tuberculosis (XDR-TB) also exists. XDR-TB is very difficult and expensive to treat.

Take Action on TB Using the EPIC Format

Ask your Senators to sign on to a letter to the Administration calling for US leadership and commitment at the UNHLM on TB.

Personalize the sample letter below to your Senators and/or use it as a starting point for a letter to the editor.

***E*ngage:** About 10.4 million become ill with tuberculosis (TB) each year, but 40% of people with this contagious, yet curable disease never receive treatment. In a globalized world, this is dangerous.

***P*roblem:** TB is the leading infectious disease killer in the world, taking 1.7 million lives annually. And our window to end TB is closing as more cases of difficult-to-treat, drug-resistant TB emerge and are transmitted.

***I*nform:** We need a new worldwide commitment to finding the untreated cases of TB, TB research, developing better treatments, and strengthening healthcare systems so we can better address TB around the globe.

***C*all to Action:** The United Nations is holding a High-Level Meeting on TB on September 26 in New York where heads of state will come together to map out new global commitments to end TB. Please sign on to the bipartisan Senate letter to the Administration calling for US leadership at the High-Level Meeting on TB. If the US shows up with conviction, other nations will follow. I can send you a copy of the letter.

Footnotes

1. [Global Tuberculosis Report 2017](#), World Health Organization
2. Ibid.
3. Thornton, J. (2018). Nine in 10 children who die from TB went untreated. *BMJ* 2018;361:k2345
4. Snow, K. J., Sismanidis, C., et al. (2018). The Incidence of Tuberculosis Among Adolescents and Young Adults: A Global Estimate. *European Respiratory Journal*, 51 (2) 1702352
5. Zenner, Dominik, et al. (2012). Risk of Tuberculosis in Pregnancy: A National, Primary Care-based Cohort and Self-controlled Case Series Study. *American Journal of Respiratory and Critical Care Medicine*, 185 (7)
6. Tuberculosis Key Facts, World Health Organization, June 2018, <http://www.who.int/news-room/fact-sheets/detail/tuberculosis>
7. Ibid.
8. United Nations Calendar, <https://www.un.org/pqa/72/event-latest/fight-to-end-tuberculosis/>
9. [Global Tuberculosis Report 2017](#), World Health Organization
10. [Global Tuberculosis Report 2016](#), World Health Organization
11. Friedrich, M. (2017). Tuberculosis Update. *JAMA*. 2017;318 (23):2287. doi:10.1001/jama.2017.18477

A Patient's Story

"I worked in a children's hospital ward as a dietitian where I contracted drug-resistant TB, diagnosed by a lung biopsy. The medication to treat the TB caused me to go into a coma due to liver failure—which nearly killed me. For 75 days, I was hospitalized. I was completely bedridden and suffered physically, vomiting and having diarrhea. Emotionally, I struggled to cope...If I felt so overwhelmed despite having support from loved ones, kindness of hospital staff and access to good medical care, how do the majority of people with TB, who do not even have food on the table to eat get through this? The truth is, any of you could have been in my place, as TB spreads through the air and can affect anyone. I am young, and as a future mother, want my children to have a bright future - it is critical that this unique moment of having a UN HLM on TB is effective to bring change."

– Ingrid Schoeman, TB Proof, South Africa

Leading with Action: Letter-Writing Workshop Agenda & Guide

Below is a sample agenda and script that you can use to put people in your community into action. We know that when people take action they are inspired. The agenda below would require a meeting of roughly 60 minutes. Adapt the elements to fit your style and timeframe.

I. Setting the Stage – 15 Minutes

2 min: Welcome and acknowledge people for being there.

“Thanks to all of you for coming. There are a lot of ways you could be spending the day, and I want to thank all of you for coming out and learning more about how YOU can play a role in the movement to end poverty. Can the RESULTS volunteers briefly say their name and how many years you’ve been involved? Also, can you all be sure to sign our sign in sheet?”

3 min: State the purpose of the meeting.

“Our purpose today is to inspire you all about the difference you can make, working with others, to create the political will to end hunger and poverty. In the next few minutes, we’ll . . .

- Learn a bit about RESULTS, the group organizing this.
- We will learn about an issue of poverty.
- We will take powerful action on the issue: we’ll write personalized letters on the leading infectious disease killer in the world—TB. Later we’ll hand-carry the letter to our Senators in Congress
- Finally, we’ll see who is interested in continuing to make a difference with RESULTS.”

10 min: Center the room and do introductions.

“Let’s see who’s in the room tonight and get in touch with why we are here. Please give us your name and tell us briefly why acting on issue of poverty is important to you.” Other possible questions, “What are you committed to in life?” or “Who do you want to be in the world?”

Afterward, “Thank you all for sharing what is important to you. We have a lot in common.”

II. The Basics of RESULTS – 10 Minutes

RESULTS is...

“So, what is RESULTS? RESULTS is movement of passionate, committed, everyday people. Together we use our voices to influence political decisions that will bring an end to poverty. As volunteers, we receive training, support, and inspiration to become skilled advocates. In time, we learn to effectively advise policy makers, guiding them toward decisions that will improve access to health, education, and economic opportunity. Together we realize the incredible power we possess to use our voices to change the world. “

Show the video if you have time: We Have a Vision: http://www.results.org/blog/we_have_a_vision/

1. Share an example of success: We protected development assistance for FY2018 after the President proposed cutting it by 30%. We worked with Republicans and Democrats to help

secure the highest number ever of congressional supporters for AIDS, TB, and malaria; global education; and maternal & child health, sending a message to the President that these programs should be protected and strengthened.

2. A local example of our role in creating change is: We moved Rep. _____ to sign on to xxx letter as part of this. He/She met with us in _____ (month) of 2018, which was key in getting his/her support.

A few more details if you have time:

- RESULTS partners meet twice per month to plan and take action.
- During one of those meetings, we connect to a national webinar to learn more about an issue, learn to speak powerfully, and take action to influence Congress. For example in August we learned how we can insert poverty issues into the public discourse during the upcoming elections.
- We also develop plans for influencing our decision makers through face-to-face meetings, the media, and other community actions.

III. Issues & Action Component – 30 Minutes

1. Introduce the issue of TB with a story or video:
 - *Stories from Civil Society on TB*: <https://www.youtube.com/watch?v=vwFfhFBkVxE>
 - *USAID TB Story*: https://www.youtube.com/watch?v=LZHWP_K03tA
 - *TB*: <https://tinyurl.com/y9o4a99m>
 - *David Bryden's blog post on TB in Haiti*: <http://www.action.org/newsroom/blog/how-prison-conditions-fuel-the-tuberculosis-epidemic>
2. Read the August Action Sheet together, including sample letter.
3. Show people how to find their legislators and relevant contact information online.
4. Everyone writes personalized letters. Be sure to add date, name, address, email, phone.
5. Ask some people to volunteer to read their letter out loud for feedback and encouragement.
6. Let people know how/when you'll deliver their letters and invite them to join you.
7. Debrief on the action-taking—how did it feel to take action with a member of Congress?

IV. Invitation to Attend the Next Meeting & Closing – 5 Minutes

“Lastly, we are planning to have future meetings like this one to guide people in becoming powerful advocates. We’ll also be visiting our representatives and senators.

- Who is up for doing this again?
- Who knows other people or groups who might be interested?
- We are also looking for people who want to take the next step in using their voice to work with the media and Congress with our group. Who is curious about what our chapter does and wants to learn more? What about joining us to meet with Congress?
- Who is interested in learning more about supporting RESULTS financially?”

Say thank you, capture contact information: name, phone, email, address. Add them to your Action Network list and stay in touch with them. Send contact info to Ken Patterson or Lisa Marchal for the RESULTS national database as part of your group’s Action Network. Your new people will receive actions twice monthly.