



November 2025

GREETINGS!

Especially in places like the United States, with its relatively low rate of drug-resistant tuberculosis, we do not often talk about extensively drug-resistant TB (XDR-TB). TB resistant to drugs like bedaquiline, linezolid, and fluoroquinolones is now found globally, and we all need to be aware of and prepared for it. People with XDR and other forms of TB with expanded resistance have few treatment options even in the best circumstances. To address this growing crisis, an ad hoc group of front-line clinical providers and civil society members-including TB survivors and multiple members of the Stop TB USA Board-formed the BETTER Project in 2024. Since then, BETTER has produced a clinical guide of best practices and several publications, including a statement on the preapproval access to ensure access to lifesaving treatment for people with limited options.

In October, I attended the Johns Hopkins University-UNITAID meeting in Washington D.C. on pre-approval access. This diverse group of stakeholders, which included clinicians, regulatory authorities, civil society, and TB survivors, and notably drug developers, concluded overwhelmingly that we need pre-approval access to new drugs for people without other options. We will continue to work together to make a streamlined pre-approval process--one which ensures equitable access--happen. Doing so will move us closer to TB elimination and help prevent people from dying of this curable disease.

- Jonathan Stillo, PhD, Stop TB USA Chair

DC UPDATE

Shutdown edition x2: Keep/emailing your 3 members of Congress! It is time Congress reopens the government, upon which our societal quality of life depends. The Capitol Switchboard is **1-202-224-3121**; our top action is to continue to ask your Rep. and 2 Senators to ask Leadership to re-open the government & to pass \$225 million for CDC's TB programs for FY26, or at least an increase for inflation in any continuing resolution (CR):

Sample script 1: As your constituent and a public health advocate, I urge you to speak out in favor of strong funding for the CDC's TB programmatic and research funding. Since TB anywhere is TB everywhere, we cannot afford the risk of further increased rates of transmission or drug resistance. Increases in TB drug prices, let alone the three years of increased cases, all require more resources. [*Add a sentence about why you care.*] Will your boss 1.) Call on Leadership to reopen the government, and 2.) Talk to the Chair and Ranking Member of the Appropriations Committee in support of \$225 million for CDC's TB programs?

I look forward to hearing a response. [Leave phone number or email if you wish to receive a response.]

Bonus points if you write us at leadership@stoptbusa.org and tell us how your calls went!!

ANNOUNCEMENTS

- WHO releases new guidelines on tuberculosis and undernutrition
- <u>Together for a TB-free world: Financing and access solutions for</u> novel tuberculosis vaccines
- WHO consolidated guidelines on tuberculosis: module 6: TB and comorbidities, 2nd ed.
- <u>Call for nominations for Stop TB Partnership's community award 2025 "keeping the lights on and providing critical TB services to people with TB"</u>

Other Opportunities:

- <u>National Institute of Allergy and Infectious Disease (NIAID) needs volunteers for</u> clinical studies
- RFAs: Partnerships for TB Vaccine Development in United States | Deadline: October
 7, 2025

TB RESOURCES & REPORTS

- New report: Global Fund partnership has saved 70 million lives since 2002
- Global Tuberculosis Report 2024
- The State of Global Health Funding: August 2025
- Tuberculosis Fast Facts
- Tuberculosis Therapeutics Market Opportunity, and Forecasts Report 2025-2030
- Tuberculosis deaths in the United States, 1953 to 2022 Our World in Data
- CDC's 2024 Global Health Impact: By the Numbers
- Provisional 2024 Tuberculosis Data, United States TB in the News

TB Incidence Reports:

- Ozark student tests positive for tuberculosis Springfield Daily Citizen
- 'A dangerous inflection point': Georgia experts say control of tuberculosis hinges on robust funding
- NH health officials identify 2 new TB cases in Manchester, Nashua NBC Boston
- <u>TB case reported at Lake Norman-area high school. What to know Charlotte Observer</u>

TB Articles:

- Elvis and Drug-Resistant Tuberculosis: The Clinical Study That Saved His Life
- We have the cure. Why is tuberculosis still around? : Short Wave NPR

- <u>Tuberculosis and Beyond: What ER Physicians Are Seeing and Why Infection</u> <u>Preventionists Should Pay Attention</u>
- <u>Cepheid Announces World Health Organization Prequalification of the Xpert®</u>
 <u>MTB/XDR test</u>
- <u>U.S. funding cuts could result in nearly 9 million child tuberculosis cases, 1.5 million child deaths</u>
- Forecasting global demand for life-saving TB vaccines Clinton Health Access Initiative
- Older adults, males, racial minorities often behind respiratory TB-related deaths in US
- Former CDC director offers an insider's 'Formula for Better Health' in new book

JOURNAL ARTICLES

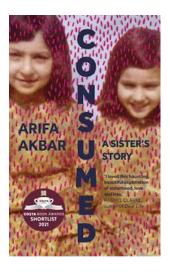
- Neutrophil proteins as potential biomarkers for a sputum-based tuberculosis screening test
- Trends in tuberculosis-related mortality among adults 35–85 years old in the United States, 1999 to 2022: a nationwide analysis
- <u>Different antibody isotypes against tuberculosis: what we know and what we need to know</u>
- The impact of digital adherence technologies on treatment outcomes, adherence, and patient-reported outcomes in tuberculosis: a systematic review and meta-analysis
- <u>Understanding the mechanisms of climate change impact on tuberculosis PubMed</u>
 Central
- <u>Targeting Tryptophan Metabolism for Tuberculosis Biomarkers and Host Directed</u> <u>Therapy</u>
- Measles, polio, tuberculosis: what's causing spikes in infectious diseases? Nature
- QuantiFERON-TB Gold Plus CD8+ T cell responses in contacts with tuberculosis disease and recent tuberculosis infection
- <u>Immunotherapy for tuberculosis: current strategies and future directions</u>

EVENTS, CONFERENCES, & COURSES

- American Lung Association Four Corners TB/HIV Conference | November 4-5, 2025
- Online Conference Session: Optimizing Workflows: Building a Foundation for Tracking and Using TB Nurse Acuity Metrics | November 11, 2025
- Mayo Clinic Decoding Class 5 TB: Navigating Diagnostic Challenges | November 20, 2025
- Union World Conference on Lung Health 2025 | November 18-21, 2025
- Monthly | SEATRAC Seminar Series

TB BOOKSHELF

Consumed: A Sister's Story By Arifa Akbar



Consumed: A Sister's Story By Arifa Akbar

Hodder & Stoughton (2021) ISBN: 978-1529347524

Evidence of how much work needs to be done to **#EndTB** even in high-income, low burden countries is that when TB survivors from those locales meet, they spend little time comparing antibiotic regimens, side effects, effects of the disease itself: instead, they swap stories about how long it took to get a proper diagnosis. Thus, it's tragic but not terribly surprising that U.K. resident Fauzia Akbar was diagnosed with miliary TB a full six months after her initial symptoms of weight loss, fatigue, and night sweats—in a post-mortem reexamination of her spinal fluid.

Her sister, Arifa Akbar, devotes much of *Consumed: A Sister's Story* to exploring why it took doctors so long to look for TB. One reason is that Britain had less than 6500 cases around the time of Fauzia's death and then only around 3% of those cases were miliary. And though born in Pakistan, a country with four times the U.K.'s burden, Fauzia had lived in Britain for almost four decades.

Another factor keeping TB out of consideration was that while Fauzia was struggling in multiple ways, including financially, she was not destitute. But even if she were, the destitute often go untested until it's too late. Francis Drobniewski, Professor of Global Health and TB at Imperial College of London and former head of the WHO Supranational Laboratory explained to Arifa, "The disease is most rife among migrants or those living invisible, impoverished lives: 'These groups are easier to forget he reflects.' They're not going to vote or appear on Question Time. They want to stay away from interacting with the state because they feel the state is not good for them."

At the same time, Arifa relates: "An infectious diseases specialist told us that 'Hampsted Bankers are getting it' [...] offering us misplaced bourgeois reassurance that the disease was not only for 'poor' people." So, given Fauzia was not currently unhoused, what went wrong with her care? Why were symptoms and concerns dismissed (for reasons other than sex and race)? Arifa examines Fauzia's medical records to see they noted her sister, "[l]ived alone with two cats, full time student (fine arts)." and that:

A narrative around her mental health builds too, charting her body dysmorphia, depression, anxiety, anorexia, over and over, with suspicions that she is taking 'toxins' as part of her eating disorder. She was contending with the prospect of eviction, frequently fell out of contact with her family.

It's as if, harkening back to Dr. Drobniewski's opinion, just as those more likely to have TB don't want to interact with the state, Fauzia didn't want to interact with institutions such as family and that was reason enough for medical authorities not to want to interact with her.²

No wonder Arifa concluded: "I am glad now that Fauzia did not bear her suffering graciously."

The relationship between Arifa and Fauzia was volatile, with the sisters sharing some emotional issues and behaviors such as binge eating. The book's subtitle "A Sister's Story", could also be "a survivor's story"-- in the context of *survived by*. Complicating the foundational questions of many grief memoirs, *Why?* and *What if?*, is the disease itself, as well as after-the-fact concerns about Fauzia infecting others who stayed close in terms of physical proximity. Arifa writes with concern for their "mother, and her sister-in-law too (who'd visited Fauzia) had eaten together, hugged, shared the same air, and my sister had had a strong cough some of the time." ³

Consumed contains recurring references to poet John Keats, who died of TB at 25: after all, the book's origins lay in Arifa's article on a visit to Rome which included a tour of the Keats house⁴ and in fact, Fauzia died within walking distance of Keat's Hamstead home where he lived after his brother Tom, whom John was caring for, died of TB. Until Tom's decline the Keats brothers' relationship was distant ⁵, but not as fraught as the Akbar sisters' leading to the inevitable, if not explicit comparison between the sibling pairs. Accordingly, the questions, Should I have done more? Could I? Would she let me? are ever present in Arifa's survivor story.

The Keats' content stops short of examining John's poetry, but Arifa Akbar is *The Guardian* theater critic, and while one could extract an undergraduate humanities syllabus from many books on TB, it's the combination of her professional and personal experience that proves rewarding as she explores the association of art with illness: from the deathbed photos of Susan Sontag by Annie Leibovitz, to Edvard Munch's *The Frieze of Life* paintings—culminating in *By the Deathbed*—, to Puccini's opera *La Bohème*, to her sister's oeuvre, including Fauzia's last embroidery:



"Its spinal columns, and ailing women seem to foreshadow her own death from undiagnosed tuberculosis which travelled fatally up her spine." ⁶

- 1. https://assets.publishing.service.gov.uk/media/5c519a7ded915d7d440c7d51/TB_Offic ial_Statistics_2017.pdf
- 2. More on the correlation of TB infection, activation, and/or failed treatment:

https://annals-general-psychiatry.biomedcentral.com/articles/10.1186/s12991-020-00281-8

https://pmc.ncbi.nlm.nih.gov/articles/PMC8637130/ https://pmc.ncbi.nlm.nih.gov/articles/PMC5759333/

- 3. Upon my own diagnosis of pTB and the conversation turning to contact tracingsomething we were all cognizant of as this was at the end of COVID lockdown-my first thought was, Did I just kill my [80 year-old] mother?, whom I just had seen for the first time in months.
- 4. https://www.tortoisemedia.com/2020/04/09/200410-the-poets-window
- 5. Nicholas Roe, John Keats: a new life (New Haven: Yale University Press 2012)

Image taken from https://tortoise-s3bucket1-1c9k2kd5zjufo.s3.amazonaws.com/original_images/px_Fauzia-last-embroidery-856x1024.jpg.jpeg, reprinted in *Consumed* with the quoted caption.

- David Moskowitz - Chair, Media Work Group

Stop TB USA: Where we unite to **#EndTB**!

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Stop TB USA

https://www.stoptbusa.org/ leadership@stoptbusa.org PO Box 260288, Atlanta, GA 31126











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