

A circular logo with a white border and a grey gradient background. Inside the circle is a stylized star with five points. The top point is blue, the bottom point is orange, and the left and right points are green. The star is centered within the circle.

Ethical Access To Care

Adriana Vasquez, MD
February 28, 2024

Screening & Treating Tuberculosis Infection
February 28, 2024
San Antonio, Texas

Adriana Vasquez, MD has the following disclosures to make:

- No conflict of interests
- No relevant financial relationships with any commercial companies pertaining to this educational activity





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University of Texas Health Science Center at Texas Center for Infectious Disease

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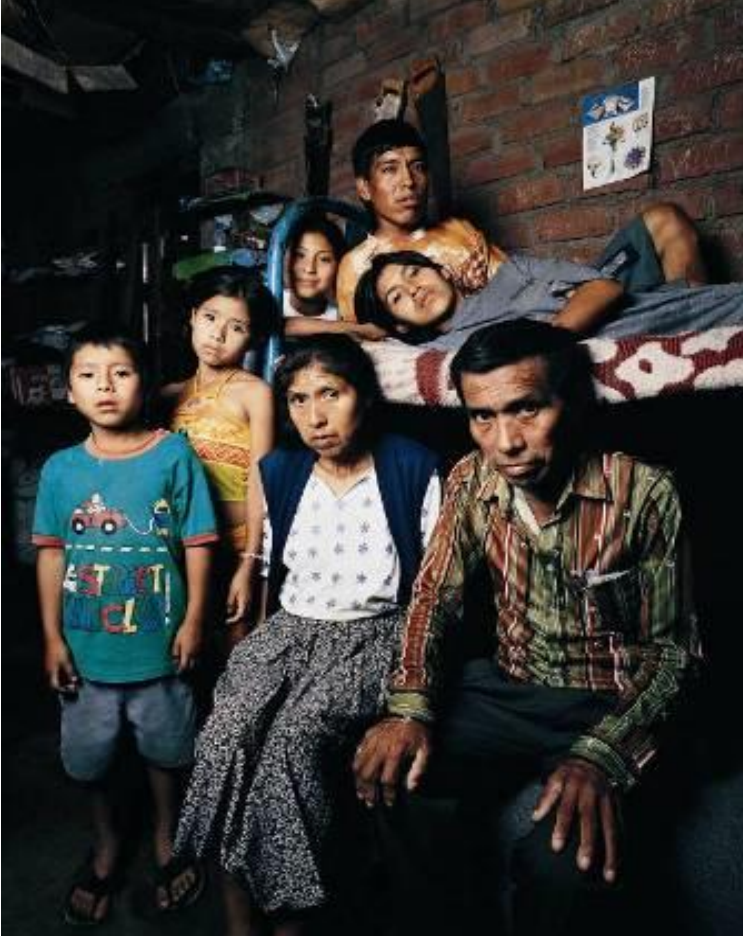
Objectives

- Discuss tuberculosis as a disease with global impact.
- Recognize that there is stigma associated with TB.
- Describe TB in those with mental illness and living with HIV.
- Discuss tuberculosis access to care and funding.
- Identify ethical issues in tuberculosis prevention, care and control.



Who carries the burden of tuberculosis? ...the most vulnerable

TB spreads in poor, crowded & poorly ventilated settings



TB linked to HIV infection, malnutrition, alcohol, drug and tobacco use, diabetes



1.3 million people died
from TB in 2022



Migrants, prisoners, minorities,
refugees face risks, discrimination
& barriers to care



Global TB Burden, 2022

- Estimated 10.6 million people fell ill with TB worldwide
- Estimated 1.3 million deaths due to TB
- Eight countries accounted for more than two-thirds of the global total: India, Indonesia, China, the Philippines, Pakistan, Nigeria, Bangladesh and the Democratic Republic of the Congo



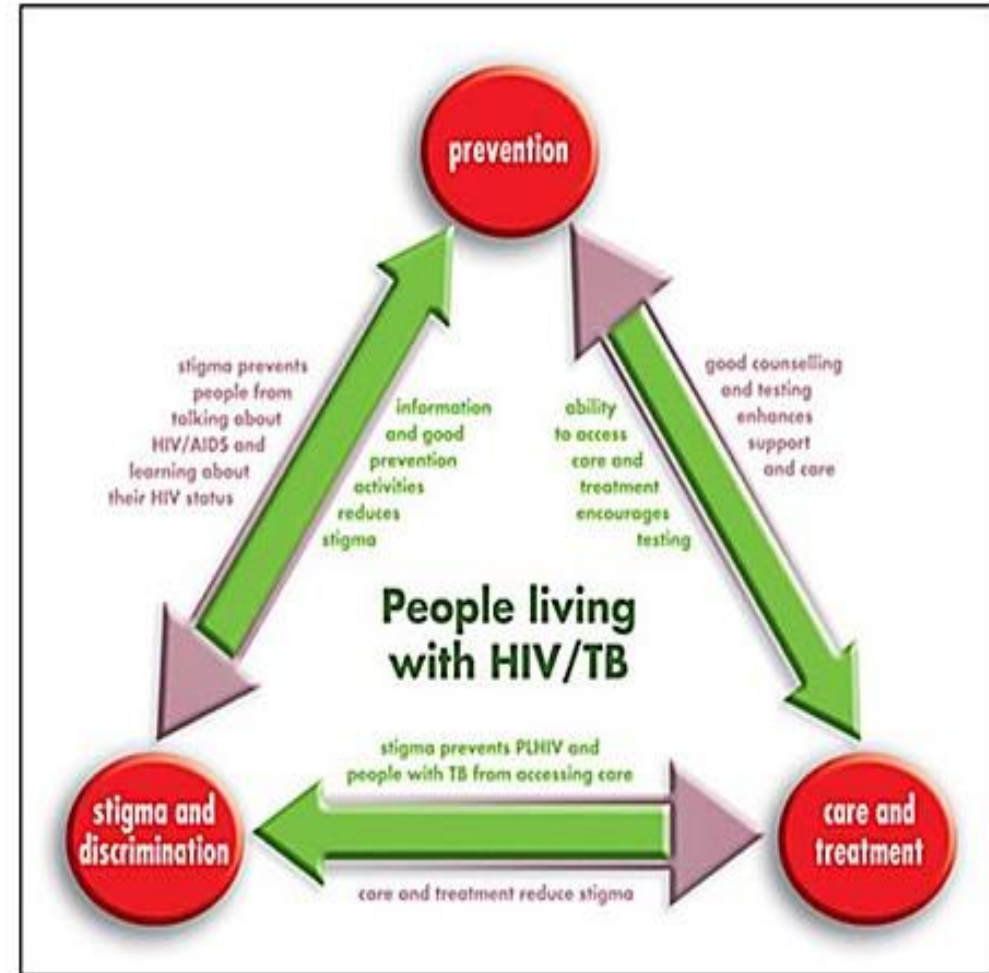
TB Situation and Response, 2022

- TB was the second leading infectious disease killer worldwide, after COVID-19.
- TB was the leading killer of people with HIV
- TB was a major cause of deaths related to antimicrobial resistance.



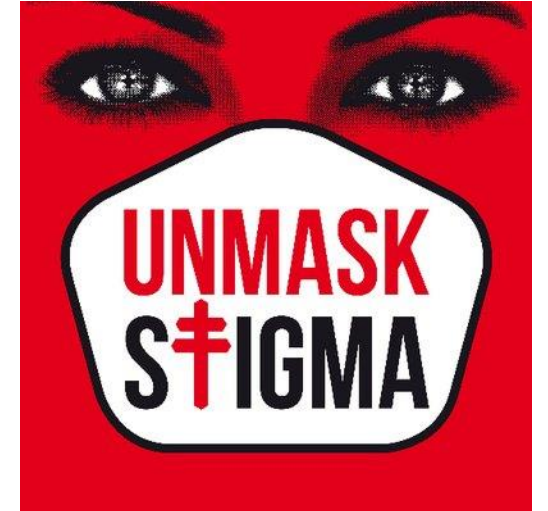
Stigma

- Prevents people with HIV and TB from
 - accessing care
 - talking and learning about HIV and TB status
- Good counseling enhances support
- Ability to access care and treatment encourages testing
- Information and good prevention activities reduces stigma
- Using non-stigmatizing language



Ending TB-related stigma and discrimination

- Reduction of stigma is essential to End TB
- Stigma needs to be addressed to achieve zero TB suffering
- New Interventions to reduce and measure stigma are needed
- **Stigma interferes with care seeking, contact investigation, treatment initiation, adherence and quality of care**



“Stop the stigma, discrimination and negligence”



Brenda, a TB Photovoice participant: “We need to put an end to stigma, discrimination, negligence and indifference. We have the science, the medication and everything it takes to STOP TB. What is keeping us from doing this?”

Voices and Images

Tuberculosis Photovoice in a Binational Setting



If you think taking care of TB can wait, consider
this...



The Spread of XDR-TB May Be More Significant than AIDS

- Being airborne, TB can be contracted via casual contact and is much more contagious
 - Behavioral modification (IV drug use, sexual contact) can prevent AIDS
- The risk to 'innocent individuals' and public health in general is greater in the case of TB

M.J. Selgelid IJTBLD 12(3);231-235 2008



TB IN THOSE WITH MENTAL ILLNESS AND LIVING WITH HIV



TB is a Unique and Painful Experience

- Patients believe that TB is always an interruption in life
 - Physically, psychologically, economically and socially
- People with TB are more likely to develop mental and psychological problems
- After the initial shock from diagnosis there is a period of denial followed by
 - Resignation and depression



Mental Illness and TB

- TB and mental illness have common associations
 - Homelessness
 - Alcohol/tobacco/ substance use disorder
 - Poor access to health care
- Patients with mental illness have
 - High risk of TB acquisition and transmission
 - Poor adherence to anti-TB treatment
- After TB diagnosis risk of mental illness increases



Depression and Anxiety are Common in TB Patients

- Symptoms of TB and depression overlap
 - Weakness, fatigue, loss of appetite and energy
- TB medications like **cycloserine** can cause agitation, confusion, depression, hallucinations and psychosis
- Depression can lead to further disability and interfere with treatment



Untreated Depression in Patients with TB

- Poorer quality of life
- Greater disability
- TB treatment failure
- Death



Treatment for depression should be provided for all patients with TB

Bull World Health Organ 2018,96:243-25



Isolation, one of the most Difficult Aspects of the Disease

- Feeling lonely, confined, abandoned
- Shame of needing to wear a mask
- Feeling dirty “like a leper”
- Isolation from family
 - Myths: Separated dishes, clothes, laundry

Chang B. Quality of life in TB: A review of English literature





Rachel, a TB Photo voice participant: “Burning this mask was very important to me. I wore it for several months and it was very painful. My peers didn’t know what my face and smile looked like. When I burned the mask, it was like getting rid of the stigma (associated with Tuberculosis). I felt free.”

http://www.borderhealth.org/files/res_1321.pdf



Socio-Economic Factors

- 31-50% of patients have financial difficulties
- 11% of children with TB affected parents abandoned schooling and 8% took up work
- Patients present late in the disease when cure is less likely and more costly
- Choose between continuing treatment and working



Failure to Address Psychosocial Needs Leads to

- Decrease adherence to treatment
- Ongoing transmission
- Higher mortality rates

– Addressing psychosocial factors and mental health needs is necessary to ensure positive treatment outcomes



Patient with TB /HIV and Bipolar Disorder

- 30-year-old Hispanic male who was referred to TCID for treatment of pulmonary tuberculosis with history of HIV infection, bipolar disorder, HCV, substance abuse and lack of housing.
 - Chest X-ray normal
 - Sputum AFB smear negative cultures positive for *MTB*, *pan-susceptible*.



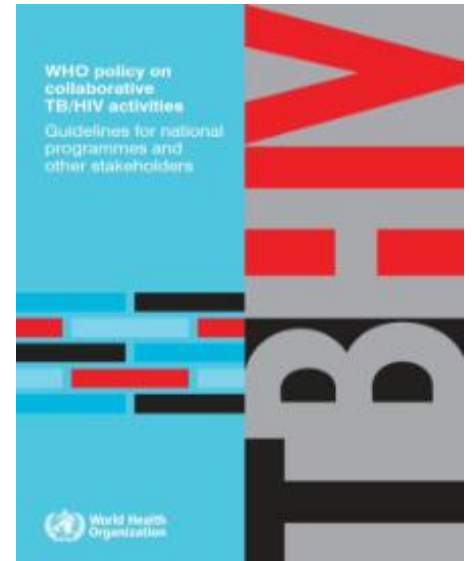
Hospital Course

- Admitted to TCID and
 - Started on INH/PZA/EMB and Rifabutin.
 - Became manic and left against medical advice
- Readmitted under court order one month later
- After 2 weeks was started on antiretrovirals
 - Truvada and Dolutegravir
- Developed immune reconstitution inflammatory syndrome (IRIS), treated with prednisone



HIV Associated Tuberculosis

- Persons co-infected with TB and HIV are 19 times more likely to develop active TB disease than persons without HIV
- Risk of progression from TBI to TB disease is 10% per year versus 10% lifelong in HIV negative patients
- TB is the most common presenting illness among people living with HIV



» http://www.who.int/tb/areas-of-work/tb-hiv/tbhiv_factsheet_2016_web.pdf?ua=1



COLLABORATIVE TB/HIV ACTIVITIES: RESPONSE & PROGRESS



- HIV testing should be offered to all patients with TB
- Antiretroviral therapy (ART) should be given to all TB patients living with HIV, irrespective of their CD4 counts.

http://www.who.int/tb/areas-of-work/tb-hiv/tbhiv_factsheet_2016_web.pdf?ua=1



Addressing The Co-Epidemics of TB and HIV

- Global HIV testing among people diagnosed with TB remained high in 2022, at 80%.
- Global coverage of antiretroviral therapy for people living with HIV who were newly diagnosed and reported with TB was 85% in 2022.



Effects of HIV on TB

- HIV and TB → AIDS-defining illness
- HIV infection accelerates TB progression
- HIV increases the risk of extra pulmonary and disseminated TB
- TB is more difficult to diagnose in HIV infected patients
 - Sputum often AFB smear negative
 - CXR may be normal

Neil A. Martinson; Proc Am Thorac Soc Vol 8. pp 288–293, 2011



Effect of TB on HIV

- TB increases the risk of death in HIV infected patients
- TB worsens HIV infection
- TB increases HIV viral load



Case Management

- Consult an expert in management HIV and TB
- Close attention to adherence to ART and TB meds
- Drug-drug interactions
- IRIS
- Side effects of medications
- TB treatment failure and relapse

» <https://www.cdc.gov/tb/publications/factsheets/treatment/treatmenthivpositive.htm>



FUNDING TB CARE



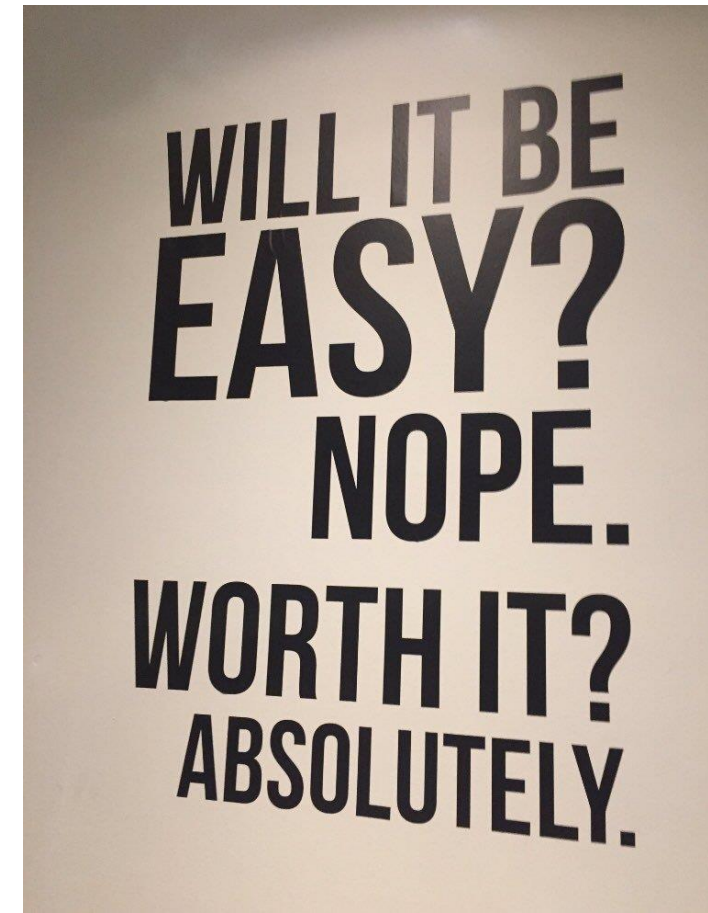
Why Are TB Patients Missed

- **No Access:** Distance to care, poverty, stigma, limited facilities, financial barriers, conflict
- **No Diagnosis:** Lack of molecular testing, culture, susceptibility
- **No Documentation:** Weak reporting, lack of notification
- **No Treatment:** Lack of meds and poor links between services



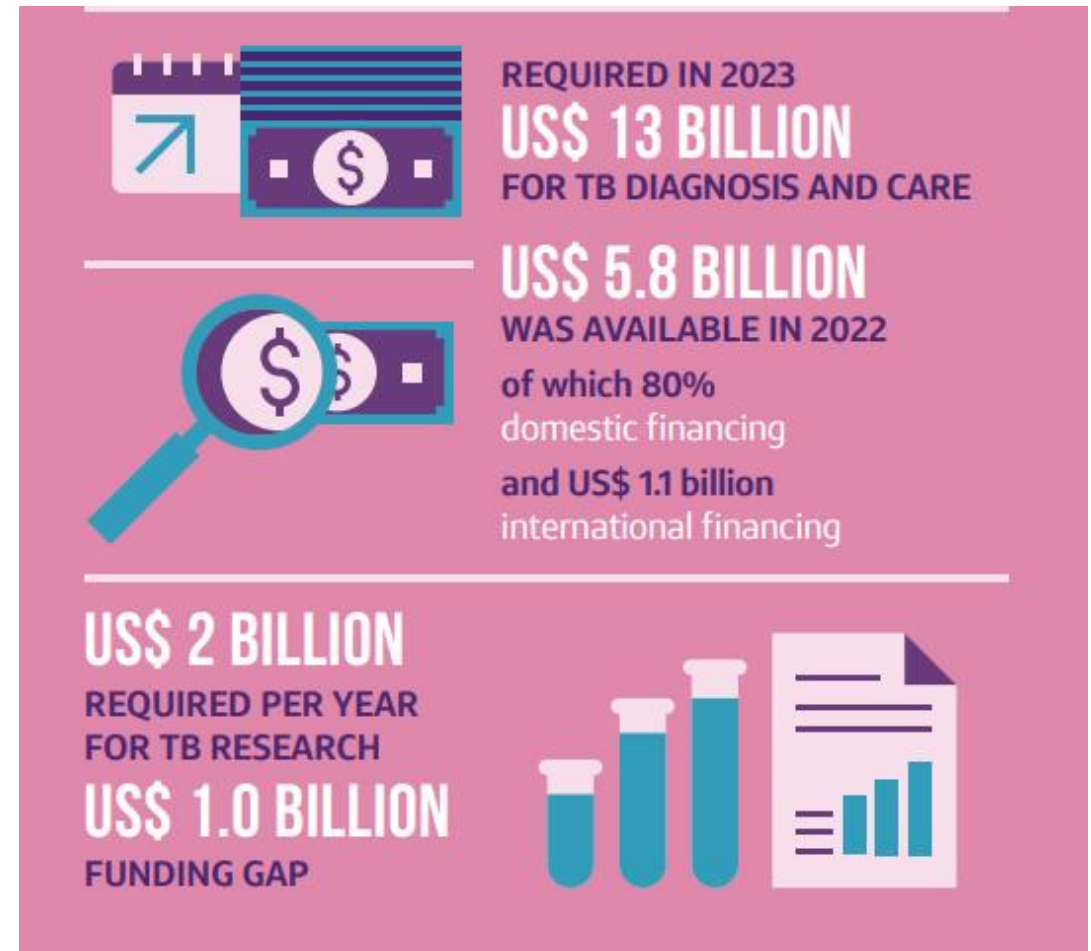
Why to Invest In Missed TB Patients

- TB is Curable with a \$30 USD six-month treatment course
- TB Respects No Borders
- For every dollar invested in TB the return is \$43 dollars
- 1 Person with TB can infect up to 10 people a year



TB Finance

- TB care, prevention diagnosis and treatment has a funding gap of \$7.2 Billion in 2023
- TB Research and Development has a funding gap of \$1.0 Billion in 2023



Distribution of Health Care Resources

- Unlike TB, AIDS requires lifelong treatment, and no cure exists
 - Full course of TB medication cost **\$20 dollars vs. \$100 per year** for HIV medications in developing countries
 - **20 million** clinical trials for **TB drugs** vs. **300 million** clinical trials for **HIV drugs**(2007)
- Advocacy for HIV/AIDS is greater than TB



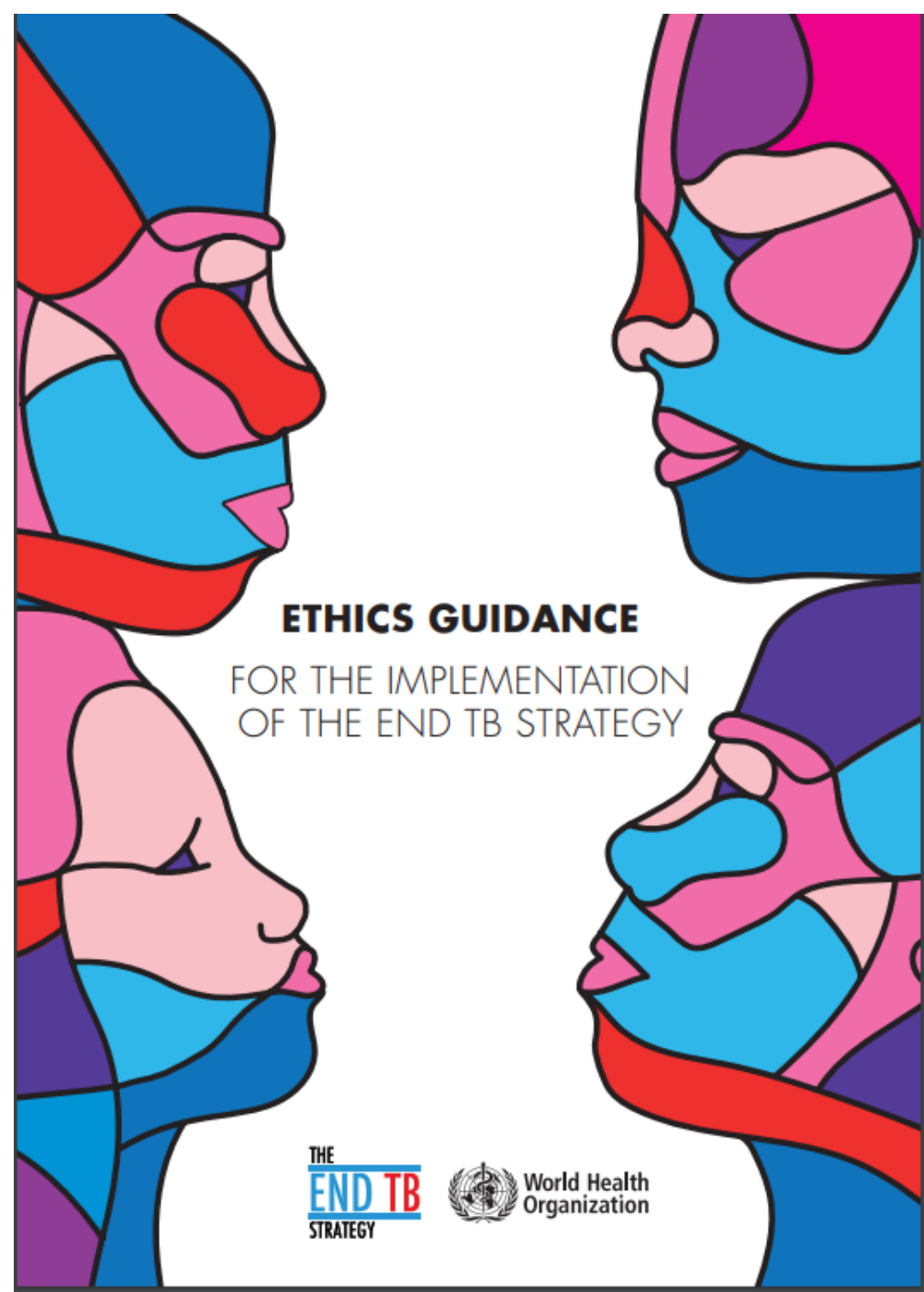
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WHO ETHICS GUIDANCE

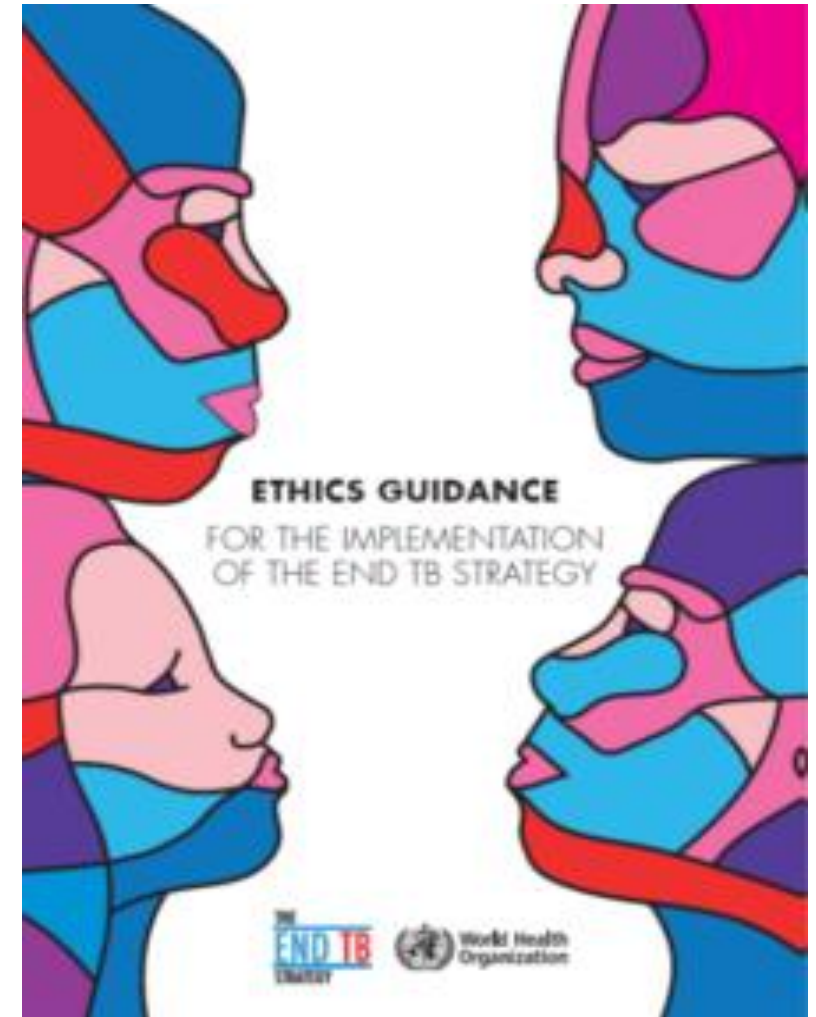


Guidance on ethics of tuberculosis prevention, care and control



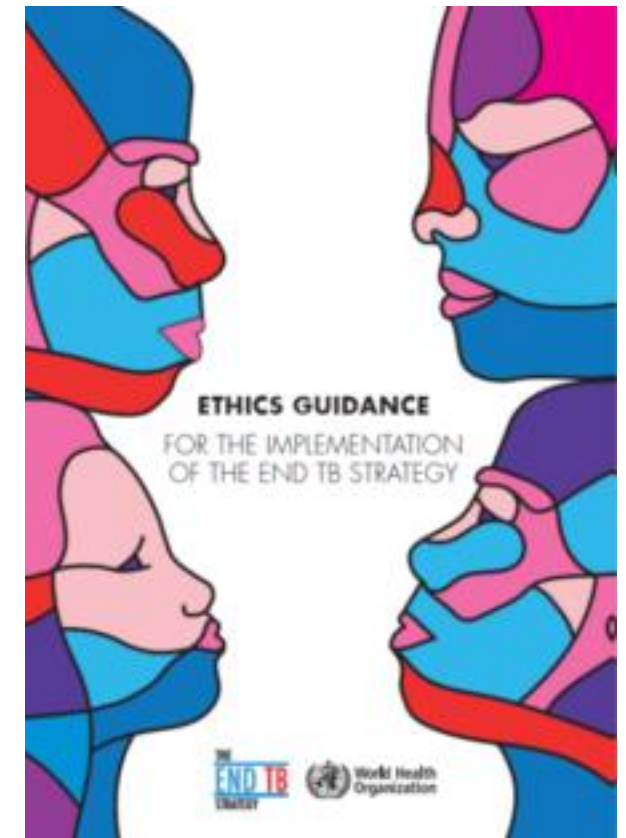
Ending TB as Matter of Social Justice

- Social inequalities drive TB
- TB drives many people deeper into poverty
- The right to health is a fundamental right of every human being



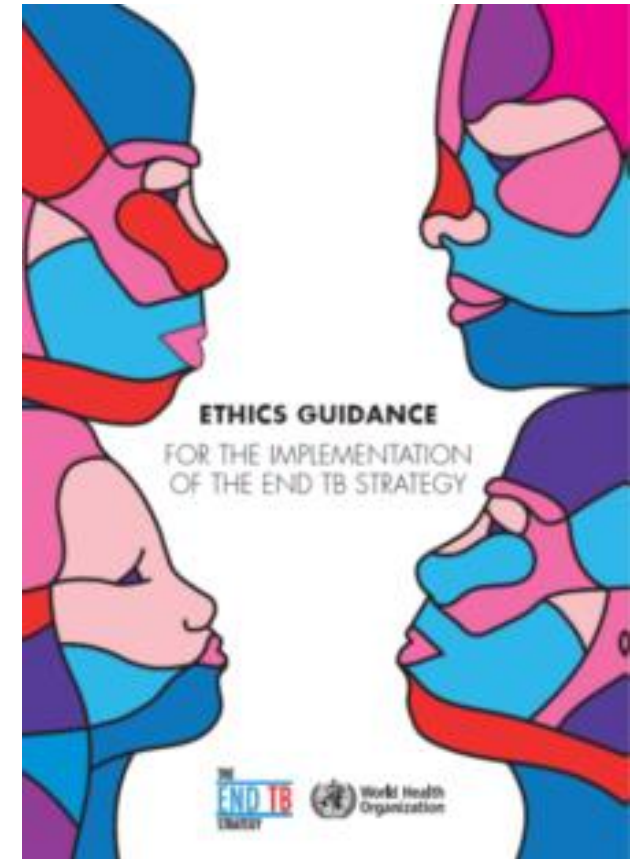
Governments Should Promote Better Access to Care

- Patient-centered approach means treatment is
 - ✓ Accessible
 - ✓ Acceptable
 - ✓ Affordable
 - ✓ Appropriate



Governments Have a Responsibility to Provide Free and Universal TB Care

- Including appropriate diagnosis and treatment of MDR/XDR-TB
- Everyone with TB should have access to the innovative tools and services they need
- Treatment significantly improve the health condition of individuals and the community by
 - Stopping the spread of a highly infectious disease.



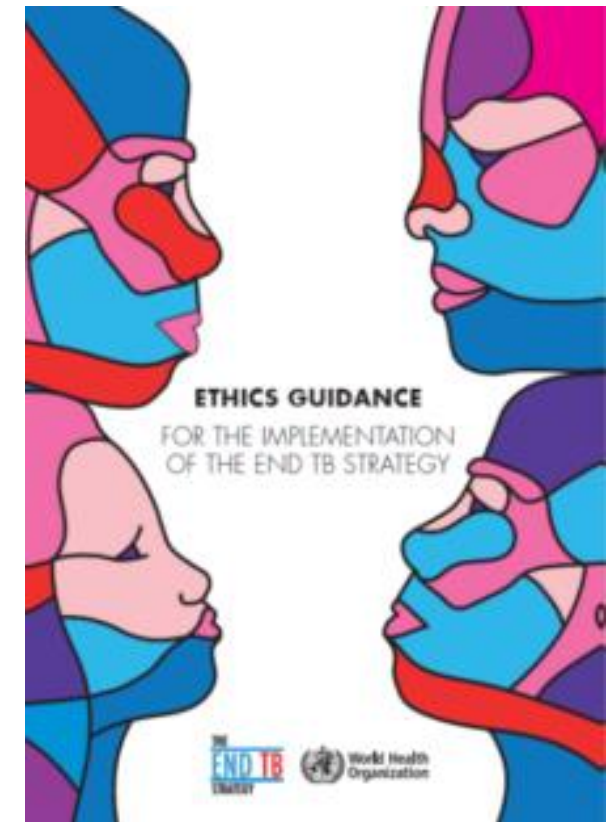
Uptake of Diagnostics, New Drugs and Regimens

- WHO-recommended rapid molecular test was used as the initial diagnostic test for only 47% of the people newly diagnosed with TB in 2022.
- The use of rapid diagnostic test remains far too limited
- WHO-recommended rapid diagnostic test is one of the main components of TB laboratory-strengthening efforts under the End TB Strategy.



Free Access to Diagnostic for all patients with TB Drug Susceptible and Drug Resistant

- Prevents patients from receiving ineffective treatment to which they are resistant
- Prevents additional spread of infection
- Prevents further development of drug-resistance
- Ensures patients are cured



Universal Health Coverage, Social Determinants

- About 50% of TB patients face catastrophic total TB costs far from the WHO End TB Strategy target of zero.
 - direct medical and non-medical expenditures,
 - indirect costs such as income losses
- Globally in 2022, an estimated 2.2 million incident cases of TB were attributable to undernourishment, 0.89 million to HIV infection, 0.73 million to alcohol use disorders, 0.70 million to smoking and 0.37 million to diabetes.



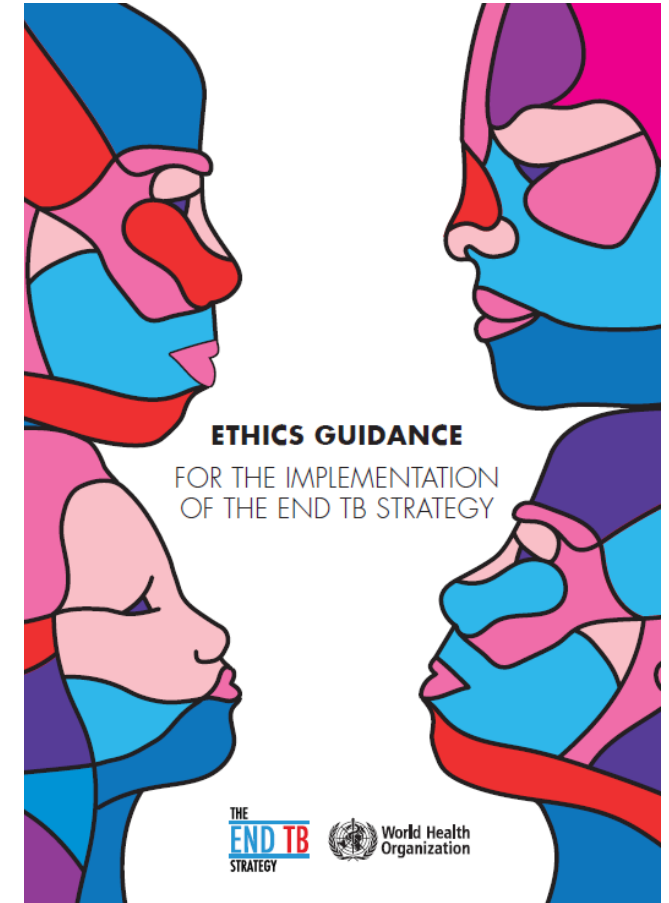
Drug Resistant TB

- Globally, an estimated 410 000 people developed multidrug-resistant or rifampicin-resistant TB (MDR/RR-TB) in 2022.
- The number of people diagnosed and started on treatment was much lower: equivalent to about two in five of those in need.
- The treatment success rate for drug-resistant TB was 63% globally



TB diagnosis in the Absence of Treatment

- Gap between number of patients diagnosed and enrolled on treatment
- Should patients be diagnosed when not treatment available?
- Should patients receive informed consent?



Risks and Benefits in Promoting Diagnosis

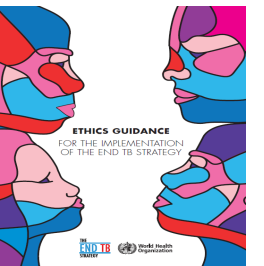
Risks:

- Stigma
- Discrimination
- Anxiety
- Isolation

Benefits:

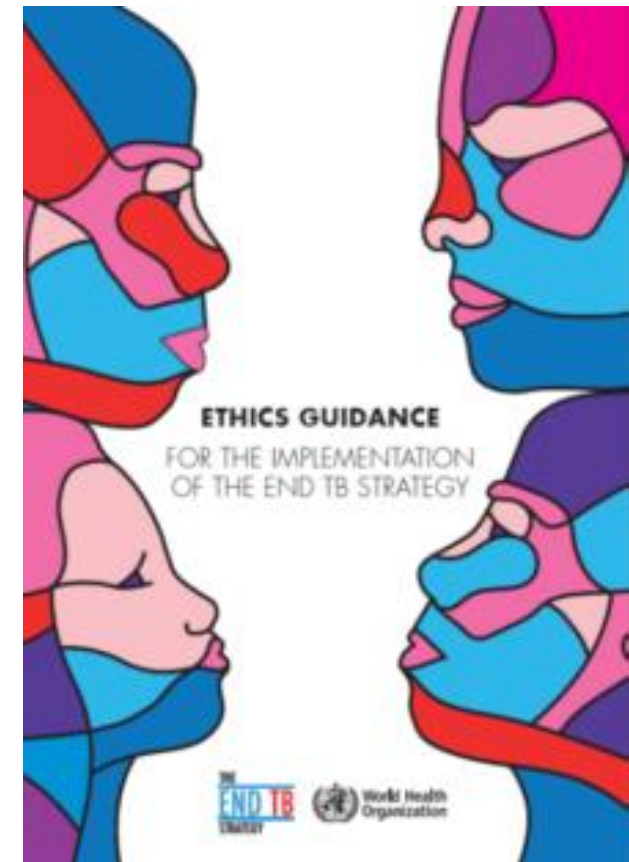
- Knowledge of condition
- Make life plans
- Prevent transmission
- Treatment?

Goal: Maximize benefits, minimize risks



Health Care Workers Have Obligation to Provide Care, but also a Right to Adequate Protection

- Health care workers have an ethical obligation to care for their patients
- Governments and health care institutions must provide a safe working environment



PATIENT DECLINED TREATMENT FOR TB INFECTION
8 YEARS LATER.....



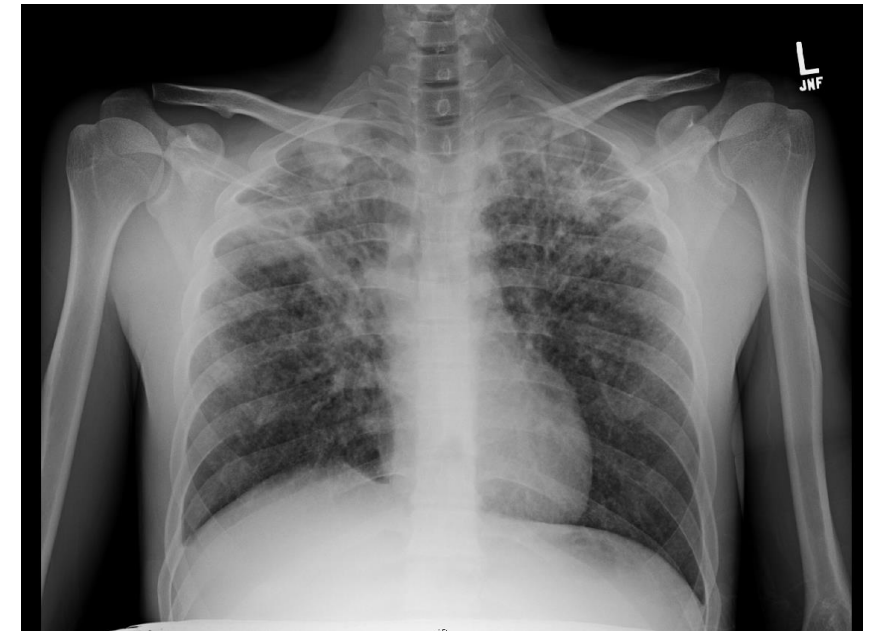
17-year-old Male with Latent TB Infection

- TST done after a TB outbreak at his school
- History of substance use disorder
- Declined treatment for TB infection with rifampin



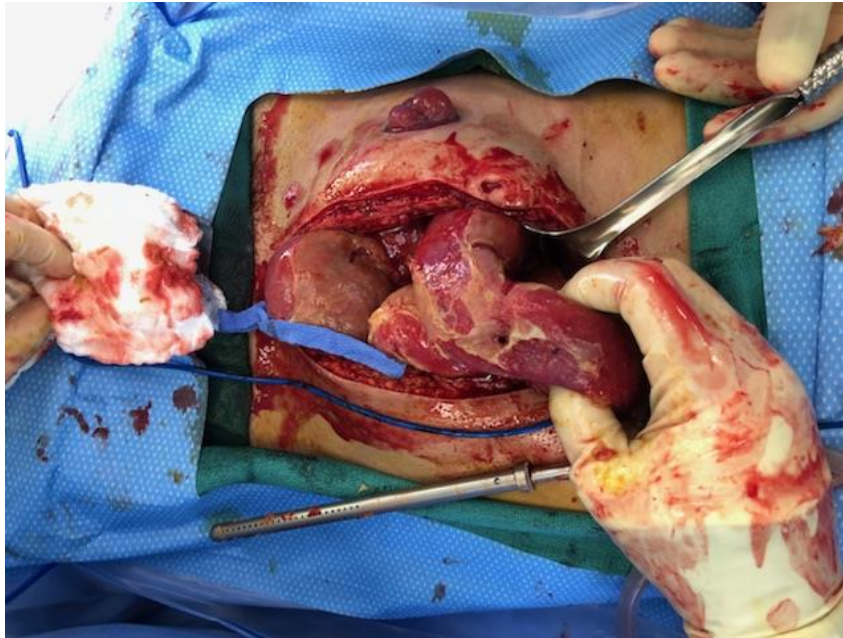
8 Years Later.....

- Admitted to the hospital with night sweats, cough and hemoptysis
- Diagnosed with pulmonary, pan sensitive TB and was started on RIPE



6 Weeks after TB Therapy was Initiated

- severe abdominal pain, had laparotomy → small bowel perforation → 19cm of bowel resection with ileostomy placement

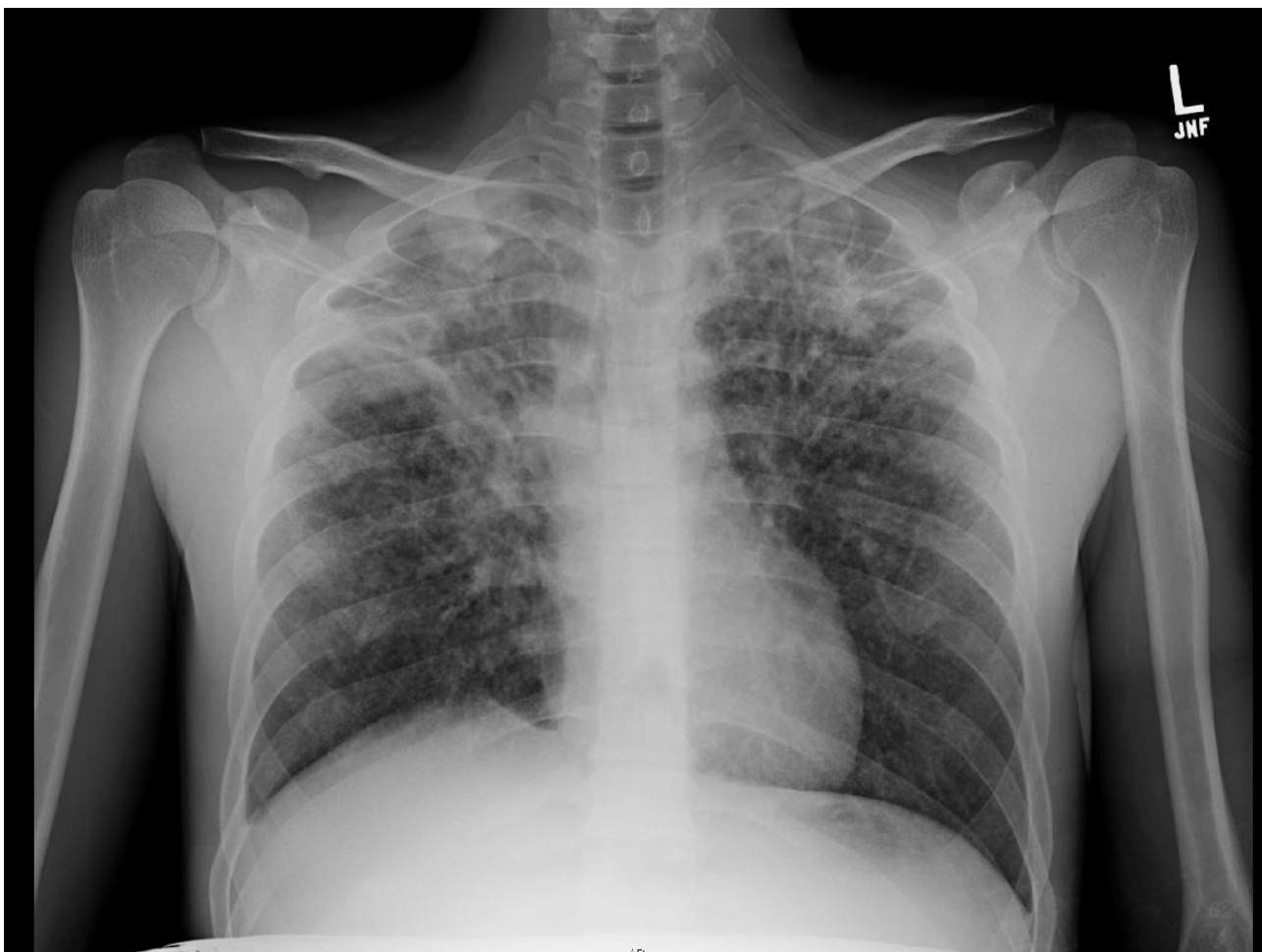


Pathology

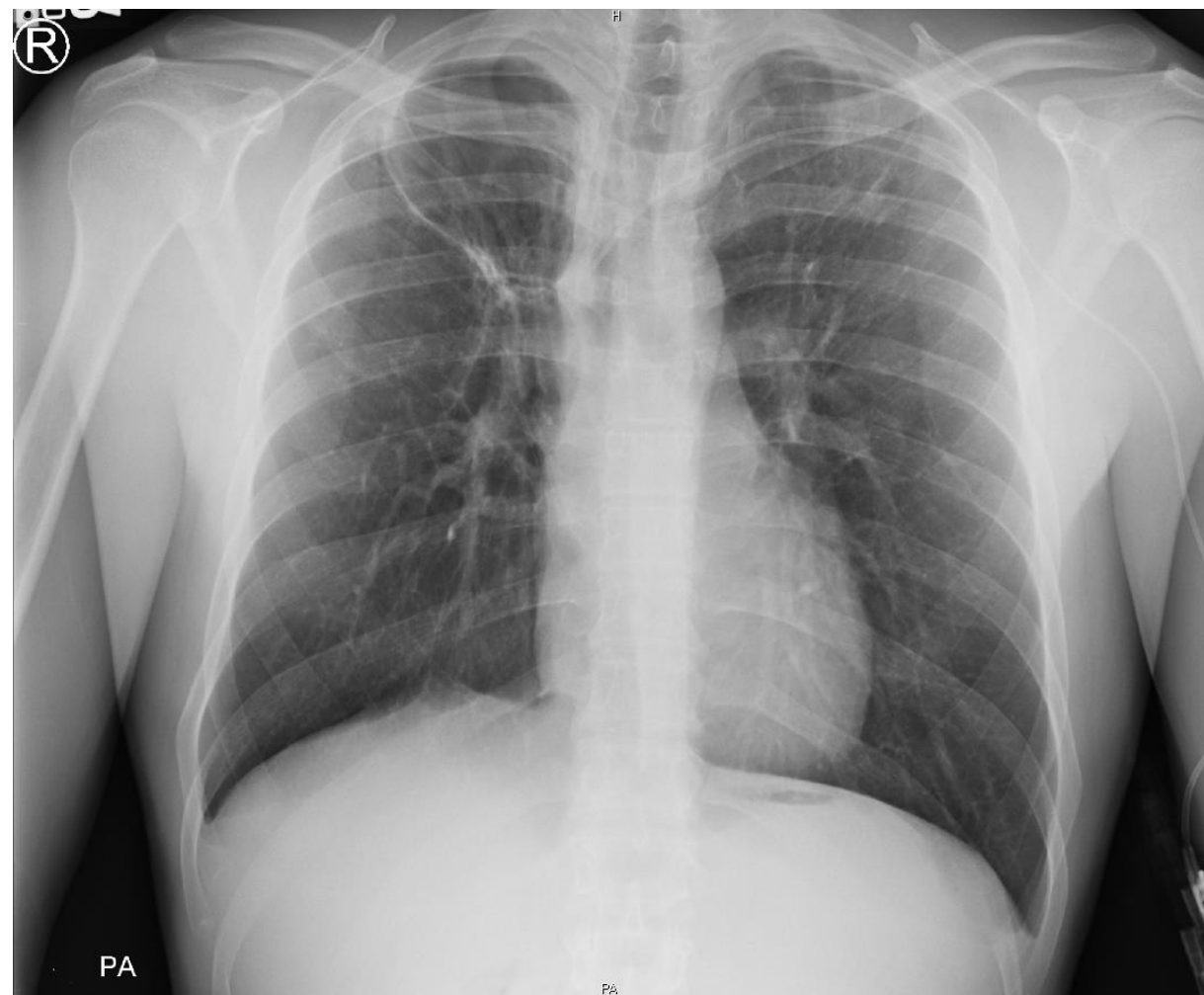
- Small bowel full thickness inflammation, perforation
- Several adhesions
- 11 lymph nodes with caseating granulomatous inflammation
- Had two additional small bowel obstruction requiring laparotomy



Baseline Nov 2017



Sept 2018



Conclusions

- Need to reduce the human suffering and socioeconomic burden associated with TB
 - Ensure treatment with dignity and compassion
- Numerous ethical reasons for wealthy nations to do more to help improve health care in poor countries.
- Infectious diseases fail to respect boundaries
 - Inadequate health care systems in poor countries threatens global public health
- MDR/XDR-TB is a serious global health threat
- Need to achieve universal access to diagnosis and patient centered treatment



PBS Frontline TB Silent Killer



<https://youtu.be/I5vW4mIFwuY?si=Q6f3wMljEEzrG5d>



Recommended Movies

- On the Lake
 - Life and love in a distant place tells the true story of the TB epidemic in America in the 1900s
 - Touches the emotional impact of TB
- Infinity
 - A love affair a physicist and a beautiful woman with TB in 1941
- A Beautiful Mind
 - The price patients with schizophrenia pay and the toll it takes on their families



Questions?



LINKS AND DOCUMENTS

- WHO's STOP TB website: <http://www.who.int/tb/en/>
- WHO's Ethics and Health website:
<http://www.who.int/ethics/en/>
- WHO's activities on Ethics & TB:
<http://www.who.int/tb/challenges/mdr/ethics/en/>
- WHO Ethics guidance the End TB strategy 2017

