



Socially Incurable TB:

What Can Romania's DR-TB Crisis Teach Us
About the Future of XDR-TB?

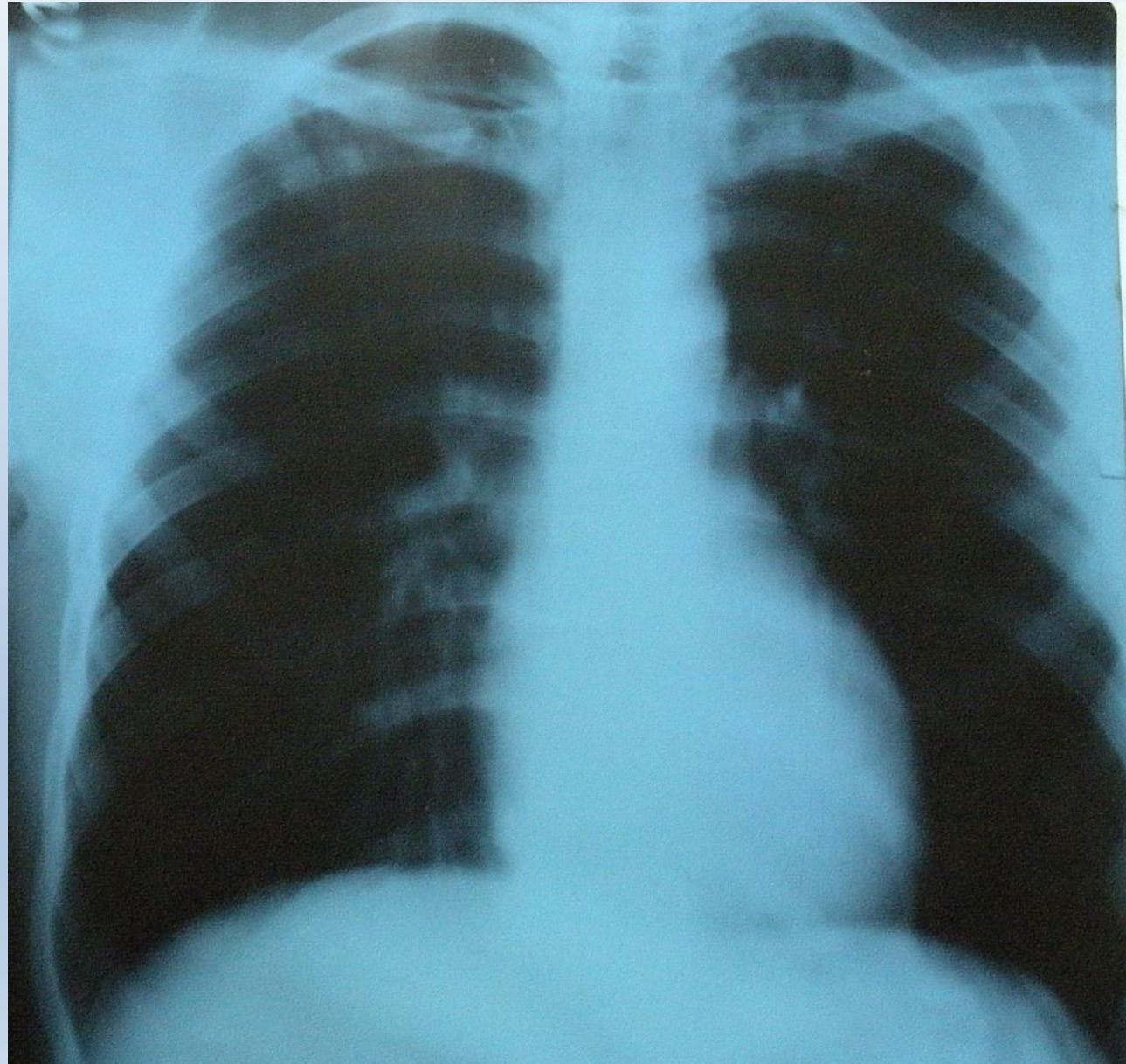
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Social Disease: What do we mean?

- TB is literally part of the definition if you look up “social disease in the dictionary.
- Poverty, but much more than that...political, legal,
- Decisions by health systems about how to organize procurement, treatment, and diagnosis are social.
- How adequate the social welfare system is and what rights people with TB have are political decisions which are also social.
- What drugs make it on the list of approved TB drugs on national formularies (and how quickly they are adopted) are also social decisions.
 - One contribution my research makes is to broaden our understanding of the social nature of TB and to shift blame away from people with TB.

The last photo of Florin

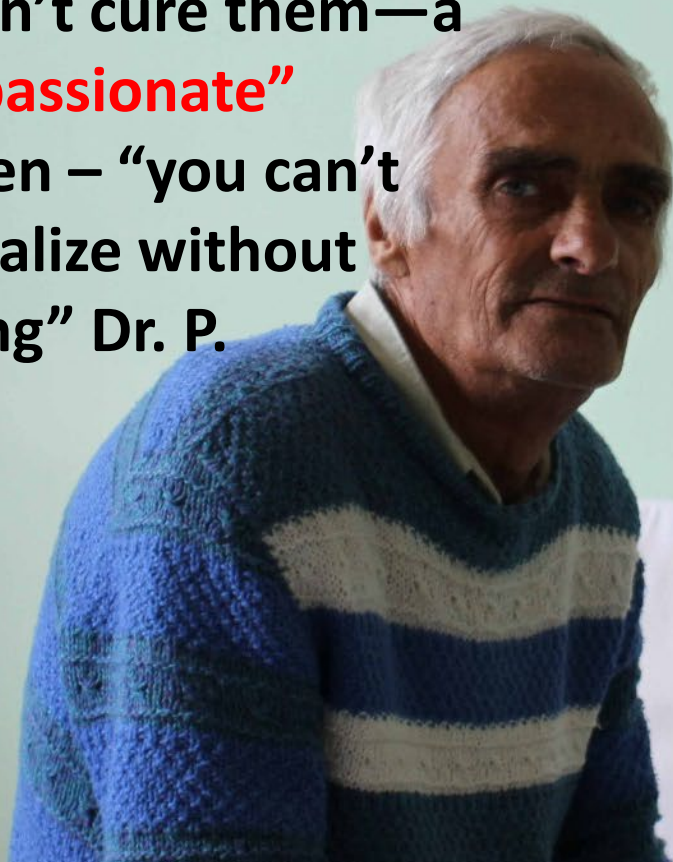
- Only 21 years old
- His father had MDR-TB.
- Treated for two months for sensitive TB waiting for his drug sensitivity test.
- He killed himself when his results came back.
- His father died months later, “tormented by grief.”





Mircea

People like Mircea with XDR-TB were prescribed drugs that doctors knew wouldn't cure them—a **“compassionate”** regimen – “you can't hospitalize without treating” Dr. P.



“They say, but no one does it, that those who don't have any more therapeutic resources should not receive any medication ... but so far I haven't seen any doctor to have had the courage to not try anything anymore.”
Dr. I.



Bootlegging XDR-TB Treatment

- Doctors and people with TB started working together to figure out a short term solution to linezolid inaccessibility:
 - Asking doctors in other EU countries to accept Romanians with XDR-TB.
 - Finding “creative” ways of obtaining necessary, but unavailable medications. This allowed some to access BDQ.
 - **But what about equity?**

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To Conclude:

1. If rapid and comprehensive drug-susceptibility testing is not accessible to all,
2. If TB treatment is guided by what drugs are available, rather than what treatment is best for the person,
3. If future DR-TB drugs are not accompanied by well-planned and funded pre and *post*-approval access programs,
4. If people with TB are not *enabled* to complete treatment through rights-based, person-centered social, economic, and psychological supports,

then we will find ourselves together again 10 years from now having the same conversations and with yet another new definition of XDR-TB.