USING HUMAN RIGHTS TO ADVANCE TB RESEARCH & ACCESS

TB2016 | SCIENCE + SOLIDARITY

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Photo: David Harrison for TAC

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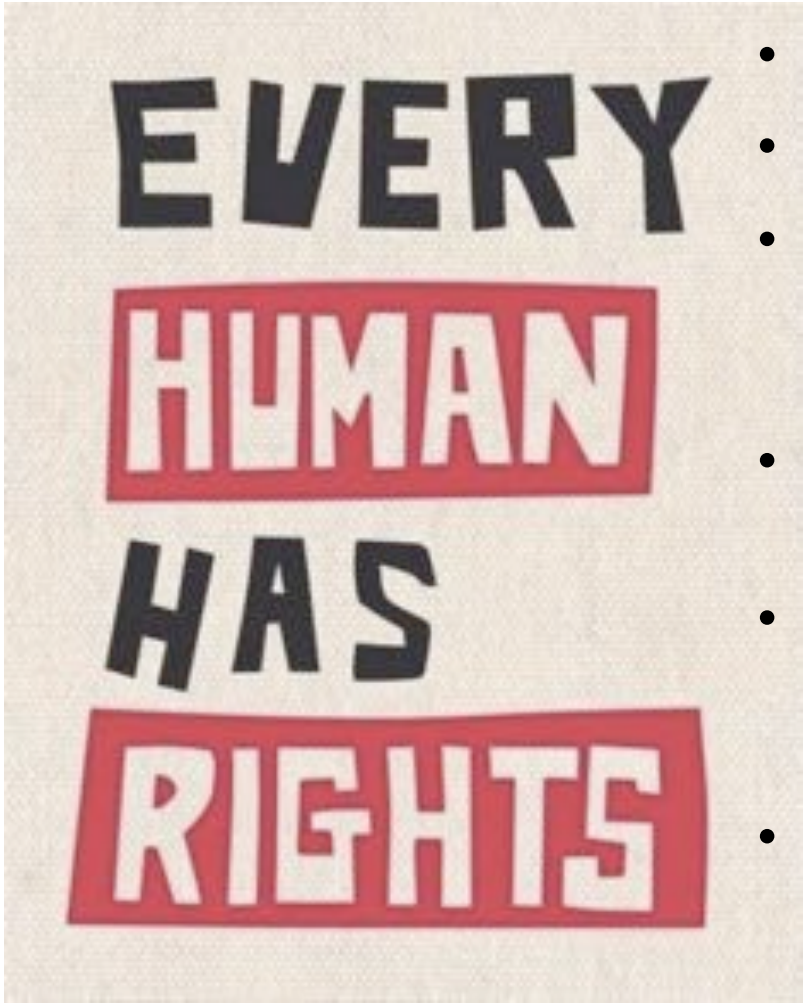
END TB STRATEGY

- 95% reduction in TB deaths by 2035
- 90% reduction in TB incidence by 2035
- Zero catastrophic spending due to TB

WHAT ARE HUMAN RIGHTS?

"timeless expressions of fundamental entitlements of the human person"



- Universal, inalienable, indivisible
- Defined by international law
- Primarily concerned with the relationship between ***individuals*** and their ***governments***
- Governments are charged to respect, protect and **fulfill**
- Rights can be civil and political (e.g., freedom of movement, religion etc.)
- **Rights can be economic, social or cultural** (e.g., the right to health, the right to scientific progress)

WHAT DO HUMAN RIGHTS HAVE TO DO WITH TB RESEARCH?

The conduct of TB research must respect medical ethics and human rights.

In addition, TB research & access to its benefits:

1. can either reinforce or resolve ethical dilemmas in TB prevention, diagnosis, treatment, and care;
2. can change the way TB is culturally perceived;
3. can galvanize advocacy and clarify legal petitions for redress of TB-related harms;
4. can either reinforce or resolve the inequities that drive the TB epidemic.

ICESCR Article 12

THE RIGHT TO HEALTH & TB RESEARCH

- Not a right to be healthy, not confined to healthcare.
- Instead, the right encompasses the provision of conditions conducive to a healthy life.
- This includes the requirement that health goods and services are available within a State party.
- Fulfilling the right to health includes “the promotion of medical research and health education.”

Where inadequate and outdated tools hinder a vigorous public health response, fulfilling the right to health may require states to ensure the availability of health technologies through the promotion of research.

ICESCR Article 15

THE RIGHT TO SCIENTIFIC PROGRESS & TB RESEARCH

- Scientific progress does not just refer to general knowledge advancement, but extends to the actual applications of such discovery (i.e. **tangible benefits**).
- All people are entitled to enjoy the right—without discrimination—and particular attention must be paid to vulnerable and marginalized groups.
- State obligations under the right include both the **development** and **diffusion** of science.

It's significant that Article 15 singles out development and diffusion as distinct—yet related—activities that exist on the same plane of concern for governments.

DEVELOPMENT + DIFFUSION

WHAT DO THEY ENTAIL?

- **Development:** "the adoption of programs to support and strengthen **publicly funded research**, the development partnerships with private enterprises, and freedom of scientific research."
- **Diffusion:** "the dissemination of scientific knowledge and applications both within the scientific community and **in society at large**. Diffusion is a precondition for **public participation** in decision-making and essential for fostering further research and applications." [1]

[1] Farida Shaheed, UN Special Rapporteur in the field of cultural rights

MEETING OBLIGATIONS TO DEVELOP & DIFFUSE TB SCIENCE

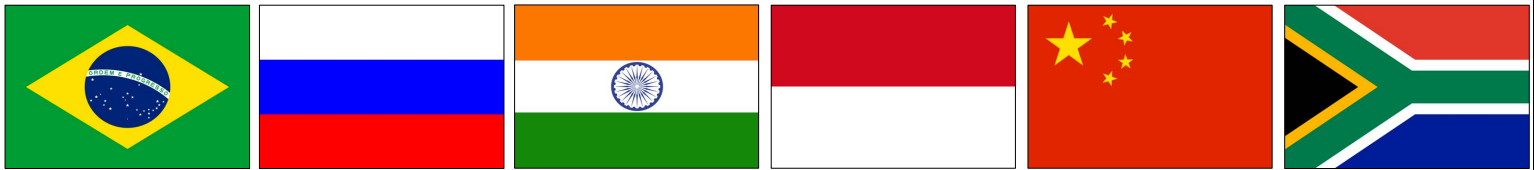
WHAT'S A GOVERNMENT TO DO?

1. Set priorities for and channel sufficient investment in a purposive development of science and technology, particularly to benefit disadvantaged groups; **Funding**
2. Develop the capacity to evaluate technologies developed elsewhere to enable importation for the benefit of constituents; **Regulation**
3. Provide opportunities for meaningful public engagement in decision-making about science and technology; **Community Engagement**
4. Create distribution systems through which the benefits of science and technology can widely reach communities; **Access Mechanisms**
5. Develop a national plan of action with a timetable and goals to rectify existing inadequacies; **Accountability Mechanisms**

Audrey Chapman, *J. Human Rights*, 2009

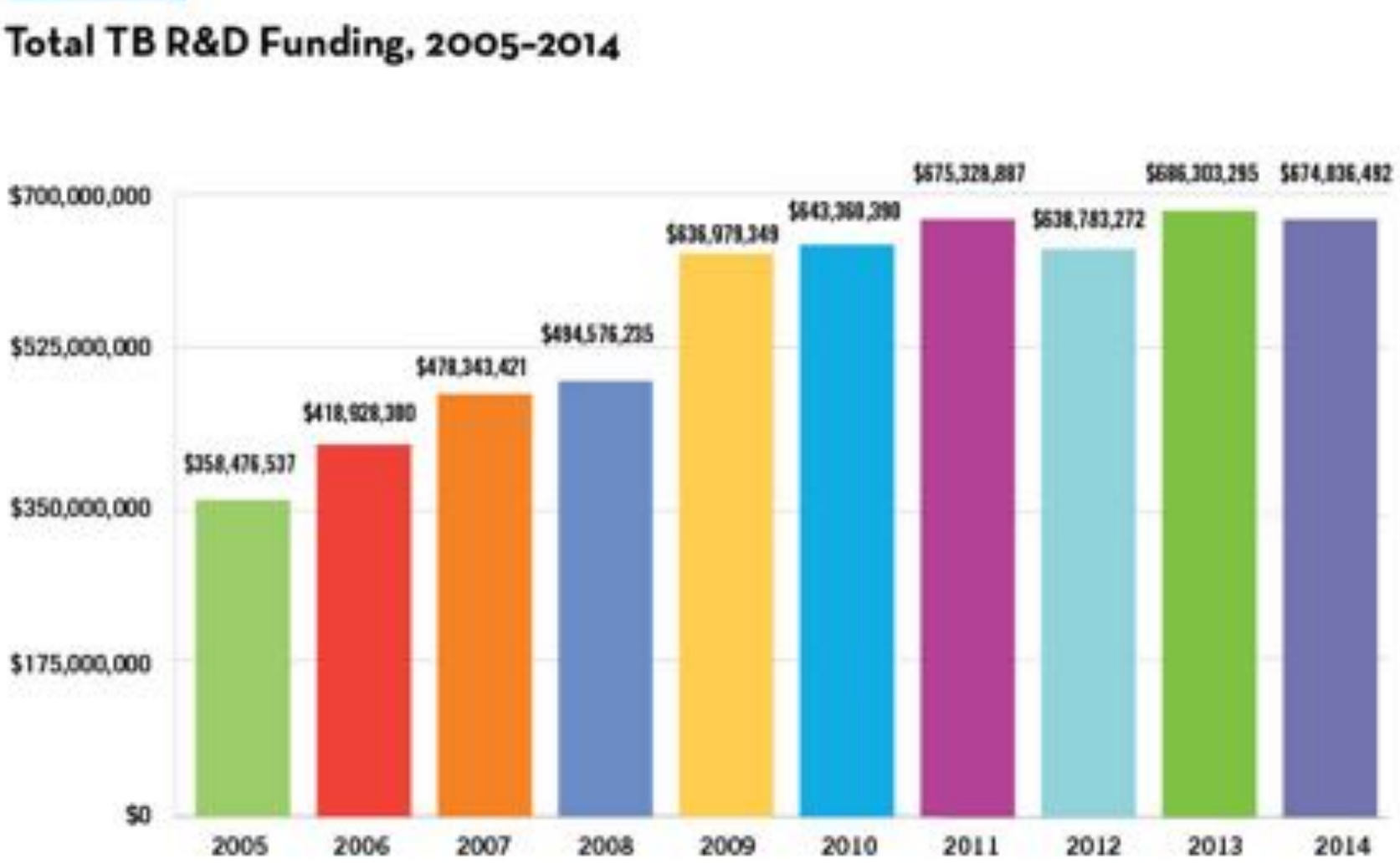
"**We say to the government of China**. We say to President Xi Jinping. Your people are dying of TB. **Why are you not investing in TB research? We say to the government of India**. We say to Prime Minister Narendra Modi. Your people are dying of TB. Why are you not investing in TB research? **We say to our government here in South Africa**. We say to President Jacob Zuma. TB is killing your people. Why do you invest less than R100 million per year on TB research?"

—Anele Yawa, 46th Union World Conference on Lung Health



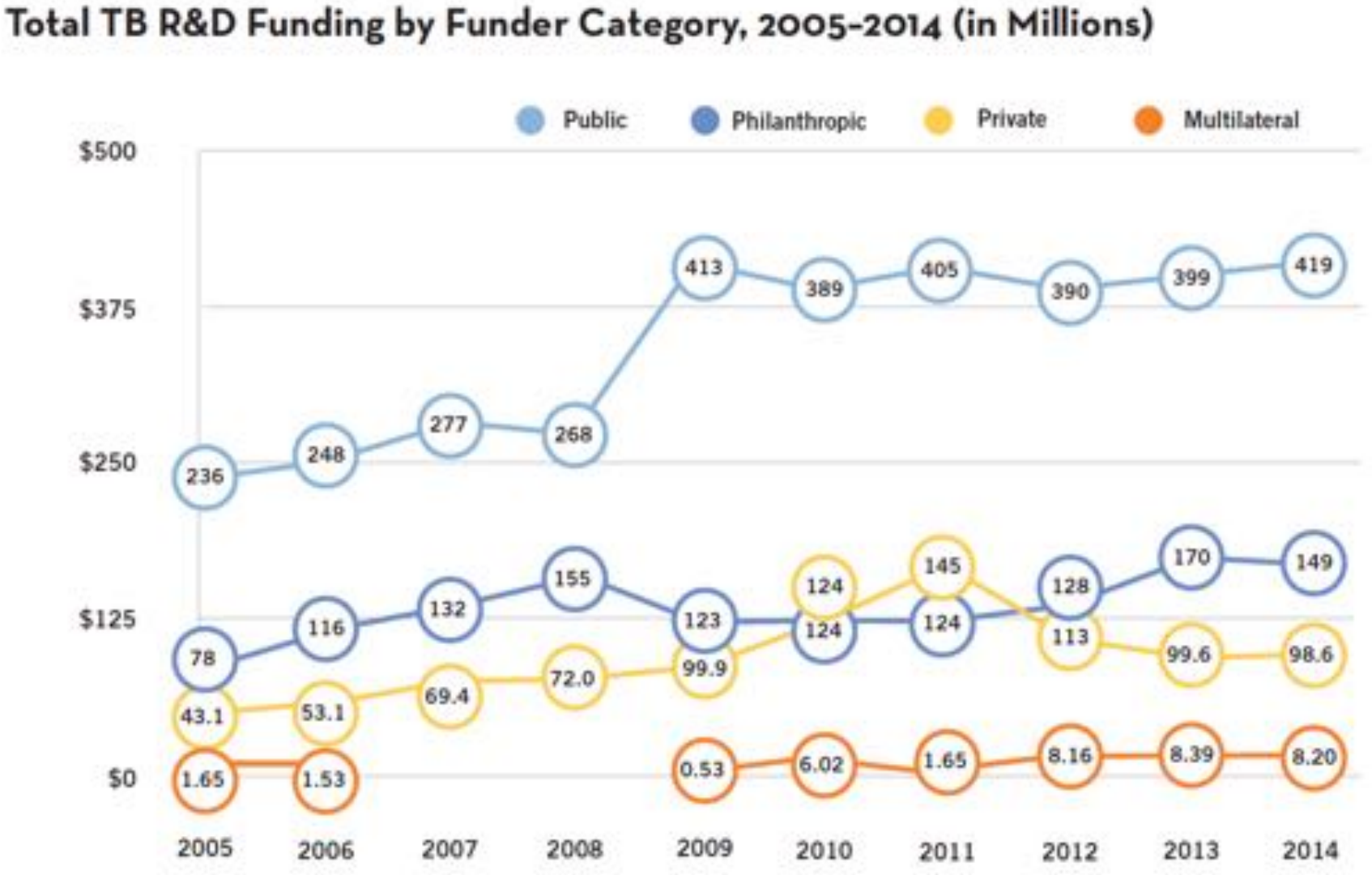
FUNDING
(DEVELOPMENT)

"WORKING IN TB RESEARCH HAS LONG MEANT LABORING WITH TOO LITTLE AND WAITING FOR WHAT COMES TOO LATE."



TAG 2015 *Report on TB Research Funding Trends*

FUNDING FOR TB RESEARCH RISES AND FALLS WITH PUBLIC BUDGETS



LIMITED FUNDING LIMITS THE EQUITY PROPOSITION OF TB R&D

…and means compromise is woven into the fabric of TB research itself.

1. **ex**: not studying drugs in optimal combination;
2. **ex**: little research that includes most vulnerable (e.g., children, pregnant women, people who use drugs, people with HIV, people with extra-pulmonary TB)
3. **ex**: drugs are approved with minimal data on their use (e.g., compare the number of studies behind delamanid versus ARV dolutegravir by the time each received regulatory approval)

1. Money spent on drug research:

HIV: USD 2.6 billion (2011)

TB: USD 243 million (2014)

2. Number of new drugs approved by FDA since 1987:

HIV: >37 drugs or drug combinations

TB: 2 drugs*

*Delamanid not yet FDA-approved

3. Number of clinical trials behind some of the newest drugs:

HIV: Dolutegravir, 61 trials

TB: Delamanid, 6 trials

Source: TAG *Pipeline Report*

ACCESS
(DIFFUSION)

A SURVEY CONDUCTED BY **MSF** SHOWS NATIONAL TB POLICIES GOVERNING ACCESS TO STATE OF ART TB CARE ARE **OUT OF STEP**

Of 24 countries surveyed…

- only 30% have policies to ensure rapid molecular tests are used as the initial test for everyone being evaluated for TB;
- 60% continue to offer the Category II retreatment regimen;
- 40% still require people with MDR-TB be hospitalized for all or part of their illness;
- only 12% reported having all existing drugs used to treat drug-resistant TB on their national essential medicines list;
- only 65% of countries have a process to access the newest TB drugs for TB patients out of other options

MSF and Stop TB Partnership 2015 Out of Step Report

SIGN THE DOTTED LINE

1. DIAGNOSTICS

- No out-of-pocket expenditures for TB tests
- Rapid molecular test (i.e. Xpert) is initial diagnostic for all
- Second-line drug susceptibility testing is available

2. MODELS OF CARE

- Treatment initiation: TB at primary level, DRTB at district/below
- Compulsory hospitalisation is not required
- Immediate ART is offered to people living with HIV

3. DRUG REGULATION

- NTP procures quality-assured TB drugs
- Prescriptions are required for all TB drugs (not over-the-counter)
- TB drugs benefit from accelerated registration

4. DS-TB TREATMENT

- Daily fixed-dose combinations is standard of care
- Treatment, including for children, reflect WHO guidance
- TB contacts are screened, children & PLWHA receive IPT

5. DR-TB TREATMENT

- DR-TB treatment reflects WHO guidance
- WHO recommended DR-TB drugs are on national EML
- New drugs are available via import waivers until full registration

WHAT WE NEED TO MOVE FORWARD IS…

"…an agenda for research and action grounded in the struggle for social and economic rights, an agenda suited to public health and medicine, whose central contributions to future progress in human rights will be linked to the equitable distribution of the fruits of scientific advancement."

—Paul Farmer, Pathologies of Power: Rethinking Health and Human Rights, AJPH 1999

THANK YOU!

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For the long story:

http://www.treatmentactiongroup.org/tbrd2015

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Photo: Carlos Aguilar/AFP