

## **NOTE BY THE COLLECTIVE OF ACTIVISTS IN THE FIGHT AGAINST TUBERCULOSIS IN RIO DE JANEIRO**

Rio de Janeiro, March 12, 2020

The collective of activists working in the fight against tuberculosis (TB) in the State and in the City of Rio de Janeiro hereby takes a stand and calls the attention of the relevant institutions about the serious situation that we currently live in, and demands answers on:

Locally (municipal and State levels):

1. The very serious structural dismantling of the Brazilian Unified Health System (SUS): the situation is more blatant and self-evident at the municipal level in the City of Rio de Janeiro, directly affecting the prevention, diagnosis and referral for the treatment of TB cases. This situation is faced on a daily basis by SUS' health professionals in the State and municipalities, who must care for hundreds of individuals seeking these already overloaded services. This situation directly affects clinical studies, whose enrollment of participants depends on the adequate referral of people displaying symptoms and/or who had already been deemed as confirmed cases. The current standing of the family health primary care clinics (PSF), entailed by the termination of agreements with the so called social organizations (OS), health professionals providers, has caused a clear reduction of TB testing in these basic health units, affecting the whole system and raising the incidence rates of the disease to 73 cases per 100 thousand inhabitants in the State;
2. The long (and partial) unavailability of the PPD (tuberculin) test: this fact has worsened over the last months, as published by the General Coordination for the Surveillance of Chronic Transmissible Respiratory Diseases (CGTR/DCCI/SVS/MS) in the Official Letter no. 71, of January 2020. The unavailability of the PPD tests prompted the State of Rio de Janeiro to hold back its distribution, which hampers treatment of latent TB among a sizeable sector of the vulnerable population. The announcement of supplies being brought back to normal levels in April 2020 has been viewed with some skepticism by both managers and civil society.

Nationally:

3. Failure to date by the National Committee for the Incorporation of Technologies on the SUS (CONITEC) to include bedaquiline, despite the guidelines issued by the World Health Organization (WHO) and its adoption by over one hundred countries with high and low burdens of multidrug-resistant tuberculosis (MDR-TB); Brazil keeps deploying injectable drug schemes, which cause several adverse effects and sequels, when affected people could be benefitting from less toxic and more efficient schemes. Countries with high and low burdens of MDR-TB, many of which with much lower GNPs than Brazil, have already widely incorporated this medication, whereas in Brazil MDR-TB has been expanding with neither due attention nor urgency, as pointed by preliminary data from several studies and programs. The protocol which requested incorporation of bedaquiline was filed at CONITEC on April 25 2019, with all deadlines stipulated for this agency to complete its analysis having been ignored.
4. Lack of a urinary diagnosis (LAM) in the health system, especially in tertiary units (hospitals), which may be a key tool to aid in diagnosis and treatment onset among serious, low immunity patients living with HIV, who require a swift response. The process has been dragging along at CONITEC and faces several months' waiting in line. People with high TB-HIV coinfection prevalence rates

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miss out due to the lack of this diagnostic tool, which has already been recommended by the WHO.

5. Lack of prioritization of preventive TB treatment for HIV+ patients as a precautionary, efficient tool, as set forth in the HIV/AIDS guidelines since 1993. Among HIV+ people who qualify for the preventive treatment that is due, an estimated less than 10 per cent receive it. Lack of programmatic data on the subject in this country hampers the adequate fight against the problem. Currently at the CGDR, this subject has been tackled by programs several times, with very few concrete advances. The slow adoption of new pharmaceuticals in the country also affects the advances in the preventive treatment of tuberculosis.
6. The unavailability of rifampicin in 300mg capsules and 20mg/mL oral suspension has affected treatment of adults and children with TB in the country. According to CGDR/DCCI/SVS/MS's Official Circular Letter no. 6, of October 2019, restablishing supplies only in the second quarter of 2020 sounds overly distant and vague to managers, but especially to the citizens with tuberculosis, who suffer with rationing or restrictions in the distribution of rifampicin across the states. This situation seems to indicate that it is impossible to resort to multilateral bodies to locate alternative suppliers abroad;
7. Lack of priority in the recording and incorporation of IGRA (by ANVISA and its adoption by CONITEC), which in all likelihood will significantly contribute towards diagnosing people with TB among HIV+ patients in hospital units across Brazil, a country featuring high TB-HIV coinfection loads;
8. The extinction of the Technical Advisory Committee on Tuberculosis (CTA-TB) in 2019 has contributed to a clear slowing down of the reviewing of guidelines to diagnose and treat TB in our country, when there is urgency in the reviewing and adoption of the frequently issued new guidelines by the WHO. Brazil has committed itself internationally to the United Nations High-Level Declaration for Tuberculosis to fight the disease, issued in 2019;
9. Revisions both of Resolution no. 444, of July 6 2011, which addresses the role of SUS's social control to monitor the National Tuberculosis Control Plan of the Ministry of Health, and of the Report by the Special Sub-Committee for Social Security and Family (CSSF) for Poverty Determined Diseases, at the House of Representatives, with the aim of rekindling the proposals and courses of action indicated by the documents that involve political agreements, convergence and articulation of the Unified Social Welfare System (SUAS) and Unified Health System (SUS) to fight diseases related to poverty;
10. Lack of investment in efforts which involve various academic instances of qualification for the medical profession and for health-related areas has deepened ignorance about TB among health professionals. There is a strong need to bring awareness about and broadcast the specifics of the disease to medical doctors, health agencies and community organizations, especially those assisting vulnerable populations in difficult-to-reach areas. Many of the people facing high risks of infection with active or latent TB who need to be reached are not cared for at health centers, ending up being a target of the work done by community agents and nongovernmental organizations. Involvement of these partners is key to the success of the TB response in Brazil. Limited training opportunities in clinics, laboratories and research in TB lead to loss of knowledge and expertise in TB by these players, with the consequent need to boost the educational factor;
11. The global emergence of a new coronavirus (COVID-19) as a fresh justification to impose a lukewarm, slow and bureaucratic pace to threats such as TB, as has been seen over the last few years;
12. Invisibility and dismantling of threats such as TB and aids, as per the new terminological classification by the Ministry of Health (MoH), which has

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transformed what used to be the Brazilian National Tuberculosis Program (PNCT/SVS/MS) until not long ago, recently converted into the General Coordination for the Surveillance of Chronic Transmissible Respiratory Diseases (CGTR) within the Department of Chronic Condition Diseases and Sexually Transmissible Infections (DCCI).

Internationally:

13. Contrary to the prevailing international trends, Brazil has experienced a rise in the estimated number of TB cases, from 87, in 2016, to about 95 thousand, in 2019, according to the latest Global Tuberculosis Report (WHO). According to CGTR's official data, 79 thousand new TB cases were recorded in 2018.
14. Lack of monitoring of the agreements entered in by the country during the United Nations High-Level Tuberculosis Meeting in 2019, and the implementation of the Tuberculosis Multisector Accountability Framework, which has been requested to the WHO by the member states themselves;
15. Lack of political, technical and financial support to undertake actions involving advocacy, communication and social mobilization (ACSM) through the involvement of civil society organizations (SCO) and communities;
16. The implementation of human rights policies, programs and strategies, in accordance with the Declaration of the Rights of People Affected by Tuberculosis, aiming at fighting stigma and discrimination associated with TB;
17. Guaranteeing and maintaining social protection mechanisms to people living with TB, in tune with the new Global End TB Strategy (End-TB/WHO), with an emphasis on universal, swift and free access to TB diagnosis and treatment, as well as social support to the families affected by the disease;
18. The dubious message gleaned when Dr Luiz Henrique Mandetta presides the Global Partnership to Stop TB (Stop TB Partnership), but puts the fight against TB to a slow and out-of-synch pace, contradicting global guidelines and advances.

The collective of **activists** who comprise the TB-RJ Forum, members of various community organizations which fight TB, as well as any other activists taking part in the Community Committees for Research Tracking (CCAP), SimpliciTB Brazil and other studies, is keen to discuss and contribute to these and other subjects related to the Brazilian response to TB, which, in our understanding, is out of phase with and insufficient to the urgent needs of all Brazilians.

Sincerely,

Collective of activists fighting tuberculosis in Rio de Janeiro

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Signed by:

- Community members of the TB Rio de Janeiro State Forum;
- Members of SimpliciTb Brasil CAB;
- Members of Brazilian National TB CAB in the State of Rio de Janeiro,
- Grupo Pela VIDDA-RJ (AIDS and TB NGO);
- Grupo Pela VIDDA-Niterói (AIDS and TB CBO);
- MNCP RJ (NGO);
- RNP+Carioca (Rio de Janeiro Network of PLWHA);
- AIDS Catholic Pastoral Committee in the State of Rio de Janeiro
- Women's Movement in São Gonçalo
- Niterói's Grupo Diversidade
- Baixada's Human Rights and Health Network;
- ANSDH – Health and Human Rights National Network;
- Members of Articulação TB Brasil in the State of Rio de Janeiro (ART TB BRASIL)