

Indonesia's Journey to End Tuberculosis with TB Patient Organizations

The World Health Organization (WHO) declared that tuberculosis (TB) is the deadliest infectious disease in the world. It is estimated that around three hundred people in Indonesia die every day because of this disease. This means that the number of TB deaths daily is double the maximum number of passengers on a Boeing 737-700 aircraft. The latest [WHO Global TB Report \(2018\)](#) estimated that there were 842,000 new TB patients in Indonesia every year. Among those, 36,000 are TB-HIV patients and 23,000 resistant TB cases (i.e. Multi-drug and rifampicin resistant). This situation places Indonesia as the third highest TB burden in the world after India and China. The problem is, only 53% were treated and reported to the Ministry of Health.

No doubt TB is still a threat to our nation's health even though what causes tuberculosis is known, it can be cured, and prevented. In Indonesia, anti-TB drugs, in fixed-dose combination, are provided free of charge by the Government of Indonesia in Puskesmas (primary health centers), clinics and public hospitals implementing DOTS strategy. However, this effort by itself is not enough to end TB and this goal would be much harder to attain without the support of TB patient communities.

Indonesia collaborates with Global Fund for AIDS, TB, and Malaria (GF-ATM) to involve communities as its grants' principal recipient. One of the good initiatives that have been significantly encouraged by the Indonesian government along with its partners is establishing and providing training for organizations of former multi-drug resistant TB patients (MDR-TB).

In 2015, several TB patient organizations from various provinces unite to form the Association of Tuberculosis Patients' Organization ([POP TB](#)) through the Challenge TB ([CTB](#)) project funded by USAID Indonesia. The KNCV Indonesia Foundation ([YKI](#)) also helped to establish former MDR-TB patient organizations in 6 regions. YKI also provided training related to the mechanism for reporting TB cases by the community to the government in 2017-2018.

POP TB is a sub-sub-recipient under Nahdlatul Ulama Health Institution (LKNU) and the Ministry of Health. LKNU also helps POP TB to find shelters for current MDR-TB patients. 'Aisyiyah, another religion-based health organization, is also involved in supporting former TB patient organizations. For example, 'Aisyiyah facilitated the latest POP TB meeting for its members across Indonesia and [advocating for economic empowerment](#) for TB patients.

WHO Indonesia office also plays a role in boosting the growth of advocacy activities of MDR-TB patients and assisting the [National TB Program](#) to ensure its approach becomes more patient-centered. WHO Indonesia office had helped voices of ex-patients and TB patients heard regionally. For an instance, Indonesia's TB patient organization members participated in the SEARO [Green light committee](#), a working group that reviews and discusses scientific information, programs, and professional experience of its members in the prevention of MDR-TB. Paran Sarimita Winarni, a former MDR-TB patient from Jakarta, was chosen as one of the members

of the Green Light Committee in the Southeast Asian region for the period of January 2019 until the end of December 2020.

Budi Hermawan, Chairperson of POP TB, had attended a regional-level meeting about Tuberculosis in New Delhi with the Minister of Health. Some representatives of former TB patient organizations are also involved in the Joint External Monitoring Mission on TB ([JEMM TB](#)) in 2017. Members of the former TB patient organizations regularly participate in government-held meetings, NGOs, or other civil society organizations related to TB in their respective regions.

In the past 3 years, POP TB has been a home to 16 former MDR-TB patient organizations in 12 provinces in Indonesia. Together with its partners, POP TB has conducted training for members of ex-patient organizations in case recording and organization management. Furthermore, "to increase the involvement of ex-patient organizations at the district/city level, POP TB has held four [cross-sectors meetings](#) and participated in the preparation of the Regional Action Plans", said Budi Hermawan. These meetings enabled the District Health Office, former TB patients, and other civil society organizations to think of ways how activities of TB patient organizations can be supported, especially in finding new cases and as treatment supporters of MDR-TB patients.

Budi added, "In several provinces, POP TB also conducted focus group discussions in hospitals and help cadres for contact investigation." He perceived that POP TB is also enabled to influence policy-making at the national-level through the Technical Working Group (TWG) facilitated by the Country Coordinating Mechanism (CCM) in Indonesia". Currently, POP TB operations are supported by GF-ATM. The organization is an implementing unit of the Ministry of Health's special grant recipient through the Nahdlatul Ulama Health Institution. This situation illustrates how the activities and capacity building of community organizations still highly depends on foreign funding. In addition, as the Indonesian economy is improving, international support for the prevention and control of TB in Indonesia may lessen in the next few years.

The Ministry of Health, as a technical agency, has supported training members of ex-patient organizations and encouraged their involvement in policy-making. Costs needed to end TB such as strengthening the health system, health workers, diagnostics, specimen transportation, and medicines have been provided by the Ministry of Health. However, the success of TB eradication requires costs to support other aspects of TB care such as sustaining the peer support programs, continuing patient transportation fee during treatment, improving accommodation to ensure good ventilation, and ensuring patients receive necessary nutrients to get healthy. This illustrates why a holistic countermeasure in ending TB at Indonesia requires mobilizing of domestic funding sources from actors beyond the health sector.

The sustainability of TB patient organizations' activities is very crucial because ending tuberculosis requires a high sense of ownership at the grassroots level. Without community support from TB patient organizations, the National Tuberculosis Program will find it difficult to examine the gap between policy and program implementation, and to reach populations most vulnerable to TB. In

addition, the involvement of TB patient organizations will encourage the emergence of solutions that can be mobilized locally.

Tuberculosis has caused death since the days of [Ancient Egypt](#) and has been in Indonesia since the [Dutch colonial era](#). It is time to realize that tuberculosis is not merely a health problem. Our challenge of meeting the needs of TB patients requires a synergy of solutions that entail cross-sectors cooperation. Efforts to achieve this collaboration have been encouraged by the Ministry of Health together with the Ministry of Home Affairs in December 2017 to support the acceleration of TB control. However, this cross-sectors spirit should be widespread because TB is a threat to the economic development of Indonesia, including for those in the private sector.

Indonesia's demographic bonus in 2035 will become a very heavy burden if more productive age Indonesians lose their productivity due to tuberculosis. According to a study conducted by [KPMG and RESULTS UK \(2017\)](#), deaths caused by tuberculosis in 2015-2030 will result in Indonesia losing more than 100 billion US dollars; per exchange rate in 2016. Various local actors from health agencies to faith-based organizations also sought to strengthen TB patient organizations. In addition to educating the public, finding and assisting patients, TB organizations also advocate to improve the quality of TB services at the regional and national levels.

This collaboration between NTP, service providers, and program beneficiaries must continue. It is imperative that more parties should get involved in supporting TB patient organizations, both in terms of increasing its human capital and financial resources. This can be available in the form of activities or financial support. According to Carmelia Basri, Deputy Chairperson of the Indonesian CCM-GFATM, TB patient organizations need to promote advocacy for its sustainability to potential donors beyond health sector, for example the Ministry of Social Affairs, businesses, and the Regional Government.

To achieve that, capacity building for individuals and TB patient organizations must be done systematically and well-planned. "Training for TB patient organizations' members also need to include hard skills (example: creating a logical framework, utilization of information technology, the latest TB science, organizational planning and development) and soft skills (example: public speaking, problem-solving, time management) to strengthen their institutions to improve their partnerships and develop new ones with actors from outside of the health sector," Carmelia uttered.