

Following on from the first-ever UN High-Level Meeting on TB, Yuliya Chorna, the executive director of the TB Europe Coalition, reflects on the global movement to end tuberculosis

# Can we end tuberculosis?

**T**he first United Nations General Assembly High-Level Meeting (UNHLM) on Tuberculosis (TB) in September 2018 represented a milestone in efforts to end tuberculosis, a curable and preventable disease that nonetheless killed 1.6 million people in 2017.<sup>1</sup> In an unprecedented move, heads of state and government committed to – amongst other significant objectives – working towards successfully treating 40 million people with tuberculosis by 2022; increasing overall global investments in tuberculosis research to \$2bn (~€1.7bn); removing discriminatory laws, policies and programmes against people with tuberculosis; and delivering, as soon as possible, new, safe, effective, equitable, affordable and available vaccines for all forms of tuberculosis.

The meeting came at a crucial time: global TB incidence is falling at approximately 2% a year, but will need to accelerate to a 4-5% annual decline if it is to keep pace with the 2020 milestones of the End TB Strategy<sup>1</sup> (reduce the number of TB deaths by 35% compared to 2015; reduce the TB incidence rate by 20% compared to 2015; and reduce the number of TB-affected families facing catastrophic costs due to the disease to 0%).

Working against this background is the TB Europe Coalition, a regional advocacy network of civil society organisations and individuals from across the WHO European Region, dedicated to empowering civil society within the regional response to tuberculosis and ensuring political and financial commitments to end tuberculosis.

Speaking to *Health Europa Quarterly*, the coalition's executive director, Yuliya Chorna, discusses the impact of the UNHLM, the importance of a strong civil society network, and



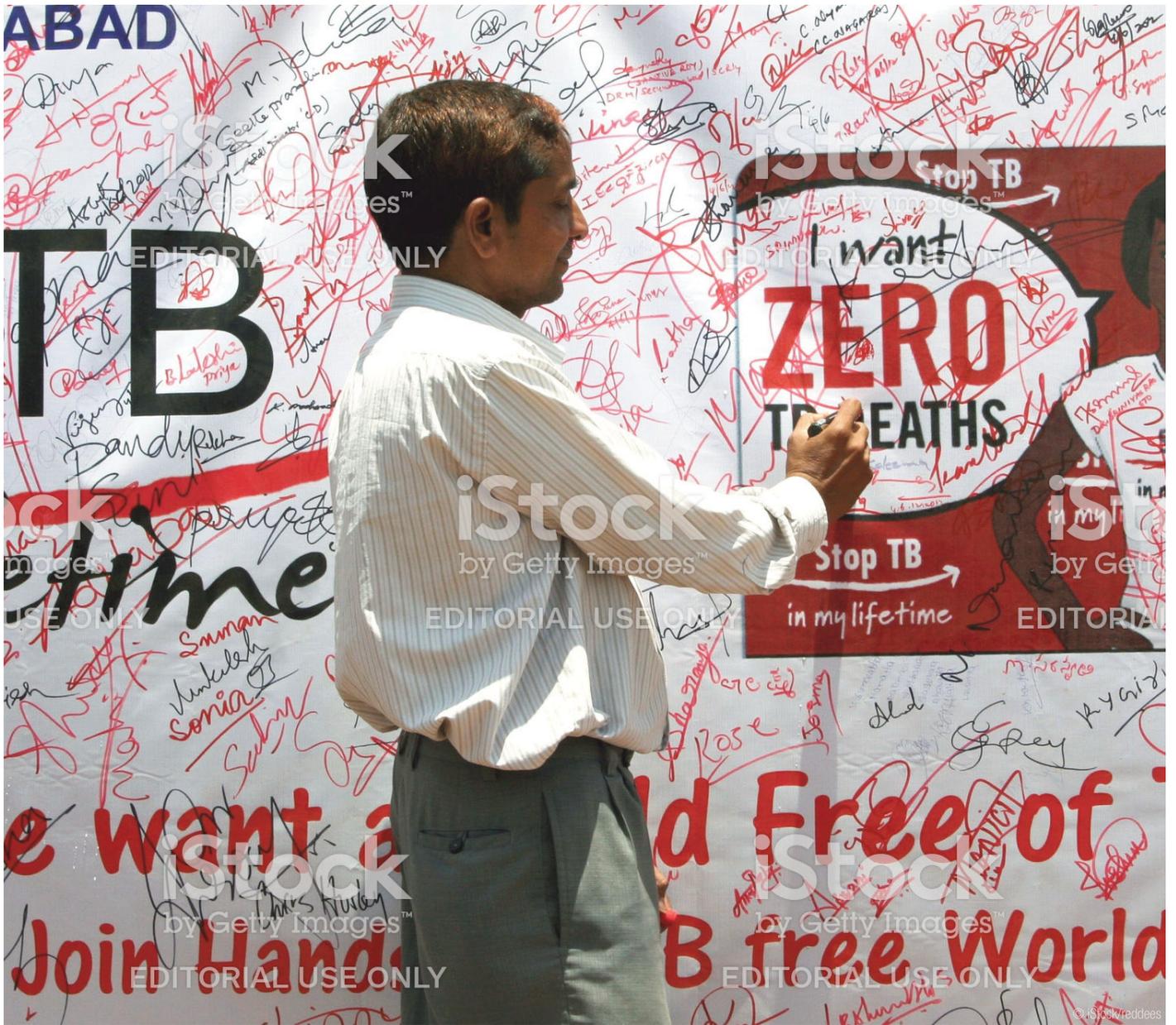
how best governments and heads of state can be held to account for their promises.

## How satisfied were you with the outcomes of the first-ever UNHLM on Tuberculosis in September?

The first ever UN High-Level Meeting on Tuberculosis was an unprecedented event for TB at the political arena. Never before have the issues of TB been discussed at such a high political level. The preparation time to UNHLM on TB was a time for unity of many civil society actors and other partners. Year-round preparatory work at global, regional and country level included developing the civil society key asks, which to a great extent are reflected in the Political Declaration, letters to the heads of states encouraging their attendance and raising the issues of tuberculosis at the countries' political arena, and setting up country delegations and ensuring that civil society is a part of them. Where these collaborative activities have happened, it has led to strengthened civil society, governmental and MP dialogue, and helped to

ensure a common vision on the position to be reflected in the Political Declaration. Global affected communities and the civil society taskforce were instrumental in ensuring linkages and co-ordination between global developments and grassroots work in the countries. The Political Declaration we received was quite strong, covering the main areas of action needed on:

- Diagnosis and treatment
- Preventing tuberculosis
- Ensuring sufficient and sustainable financing, including for research and development
- Supporting an end to stigma and all forms of discrimination
- Delivering as soon as possible new, safe, effective, affordable and available vaccines
- Developing a multisectoral accountability framework
- Providing a progress report in 2020.



However, the high-level meeting itself did not bring as many heads of states as we hoped for and particularly heads of states from the European region. That shows that much work is needed for sustainable political commitment for implementation of the commitments of the UNHLM declaration and political will to end tuberculosis.

**Are you optimistic that the SDG target of ending TB by 2030 can be met? What measures will be needed to achieve this?**

I am optimistic and I really want us, this generation, to end tuberculosis, giving a TB-free world to our children and the future generations to come. However, the approach of how we deal with TB now should be changed dramatically if we want to end tuberculosis by 2030. We should change how we find people with TB and which groups we consider to be vulnerable to it, those who need greater support in covering the current gap of one in three people with TB missed by the healthcare system, because they are either

undiagnosed or unreported. Ensuring sustainable peer-to-peer support through community and civil society involvement is critical, especially when working with the key and vulnerable groups.

We also need to change how we perceive and treat people with TB and affected communities, in line with a human rights approach. We need to overcome stigma, which so much affects access to care. Traditionally, people in many countries of the European region have been treated in hospitals for long periods from six months to two years. Patients have to suffer not only the burden and toxicity of long-term treatment with heavy antibiotics, during which time they risk cross-hospital infection with more severe forms of TB, but also being apart from their families, jobs and social lives. This should be changed in favour of quality, people-centred care, bringing the care closer to the person and making it more conveniently available. This also means addressing not only the immediate medical requirements but also the personal and social circumstances of the patients and their

families, which, if not addressed, could negatively affect the effectiveness of the treatment. These measures really help to ensure that the person undergoing TB treatment stays adherent to the whole treatment course, which in turn increases the treatment success and prevents the development of drug-resistant forms of tuberculosis.

**How can heads of state be held accountable for the actions they have promised to take in the UN Political Declaration on TB?**

At the high-level meeting, Member States committed to developing or strengthening national TB strategic plans, including through national multisectoral mechanisms to monitor and review progress with a broad range of stakeholders across different sectors. Civil society should be a part of all the processes related to multisectoral accountability, identifying specific gaps, which remains under the World Health Organization (WHO) accountability framework, driving the

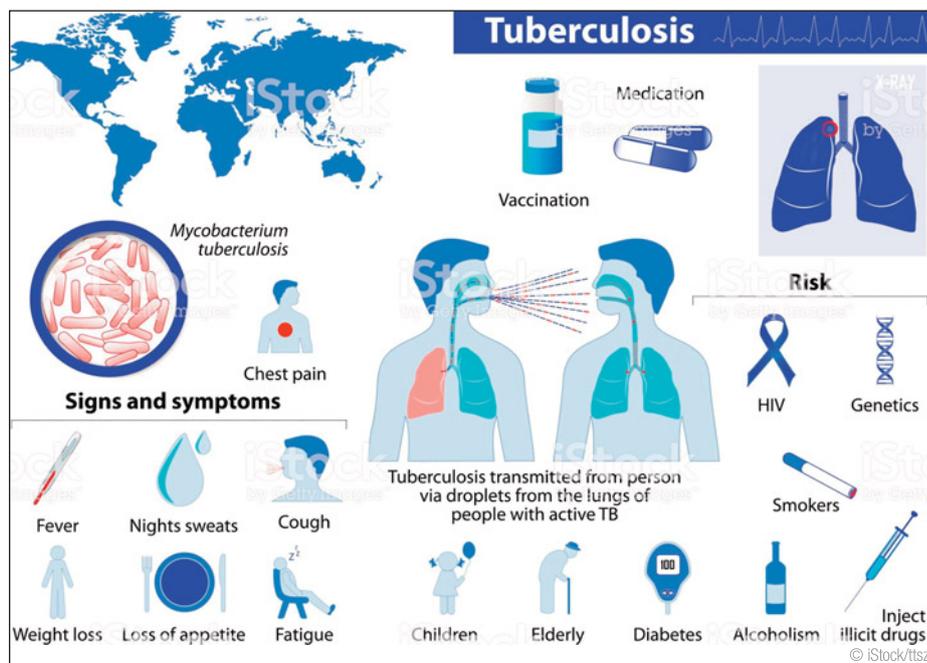
response to close those gaps, and ensuring the political will from the heads of states, government, ministers and parliaments. In most cases, civil society is well placed to initiate the countries' dialogues on the targets as well as to provide briefings on the content of the political declaration. The civil society in the countries should continue working closely with the national TB programmes to design strategies for delivering the promises of the UNHLM political declaration and adjusting national strategic plans to reach the targets needed to end tuberculosis by 2030. There should be a co-ordinated push for adoption of the WHO multisectoral accountability framework, and it needs to be ensured that the civil society is involved in monitoring and reviewing progress based on the framework. Bringing on board such supporters and key political players as members of parliaments and existing platforms of TB and other health-linked civil society organisations can really make a difference for accountability, ensuring an independent and comprehensive review of the progress made at all levels.

### What special action needs to be taken to effectively address drug resistant TB?

Traditionally, individuals with TB in many Eastern European and Central Asian countries with a high TB burden have been routinely treated in hospital on an in-patient basis for long periods. From a public health perspective, in-patient or hospital-based treatment is not necessarily an effective means of preventing the spread of TB. On the contrary, TB treatment in hospitals with poor airborne infection control measures too often contributes to the further spread of TB and multidrug-resistant TB, as well as cases of people coming to the hospital with relatively simple (sensitive) forms of TB and being re-infected with severe, drug-resistant forms. The risk of someone with TB infecting other people drops significantly in the first few days of effective treatment and is usually no longer a concern after 14 days at most, even for people with drug-resistant TB. Besides, most transmission happens before diagnosis or hospitalisation. Ambulatory care in this regard represents a key cornerstone of care that is effective to prevent drug-resistant TB transmission.

Secondly, timely access to modern diagnostics, which allow one to define the type of TB (sensitive or drug-resistant) and enable a doctor to come up with the effective treatment option, depending on the form of TB to begin with, is needed.

The next point is on availability, affordability and access to new, effective drugs for multidrug-resistant TB, for example bedaquiline and delamanid, for everyone who needs them. The introduction of new drugs should be accompanied by an effective support system for patients to stay adherent to treatment, as well as a management



system to monitor the introduction of new drugs and their effect.

Finally, the crucial thing is availability of needs-based psychosocial support for people with TB and their families. Psychosocial support (counselling, peer-to-peer support, incentives etc.) really makes a difference to both treatment adherence and treatment success. As an example, in Ukraine, patients with multidrug-resistant TB who received a psychosocial support package during the pilot project duration achieved a two-fold treatment success rate in comparison with patients who did not receive such a package.

### What more can be done to meaningfully involve civil society and communities in efforts to end tuberculosis?

The meaningful involvement of civil society is needed both for advocacy – to ensure the voices of people affected by TB are heard when decisions are made on what quality, people-centered care should look like – and in service provision. This includes psychosocial support services to ensure that the individuals take their medicines on time for the entire duration of their treatment and remain confident throughout that they will be cured. Civil society is an effective bridge between healthcare staff and hard-to-reach groups, including implementation of the active case-finding strategies for early TB detection in key populations. To ensure the sustainability of civil society efforts, especially in the EECA countries (Eastern Europe, Central Asia) facing the withdrawal of major donors' support in the coming years, there should be effective mechanisms for financing the civil society through national and local budgets.

TB training programmes on advocacy and service provision for civil society as providers of TB services

should be a part of the current TB programmes. Dialogue between national TB programmes and civil society will help to set clear roles and responsibilities between the healthcare staff and civil society/community providers and to bolster effective delivery of people-centered TB care.

To ensure political will, civil society should adopt or continue to play a crucial role in decision-making bodies at both the national and global levels. Engagement with members of parliaments as civil society focal points of the Global TB Caucus, active participation in the development and support of existing TB/health civil society platforms, being members of the national TB/HIV co-ordinating mechanisms, participation in the WHO working groups and taskforces – all of those give a stronger voice for civil society and affected communities to make a difference and end tuberculosis. For a stronger voice in advocacy, civil society should also maintain links with global and regional stakeholders and platforms such as the STOP TB Partnership, Global Fund Community Delegation, the TB Europe Coalition and other platforms – all of whom contribute to the global civil society network, advocating on post-UNHLM accountability in relevant fora and to the Global Fund, the EU and the WHO.

### References

- <https://www.who.int/en/news-room/fact-sheets/detail/tuberculosis>

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