# JOINT STATEMENT ON BEHALF OF AFFECTED COMMUNITIES AND CIVIL SOCIETY ON THE OCCASION OF THE FIRST UNITED NATIONS HIGH-LEVEL MEETING ON THE FIGHT TO END TUBERCULOSIS

### 26<sup>th</sup> of September, 2018 New York, New York

We, the undersigned members of communities affected by tuberculosis (TB), civil society organizations and networks, and individuals, recognize and appreciate this momentous occasion of the first United Nations High-Level Meeting on the Fight to End Tuberculosis. We wish to particularly thank and commend the co-facilitators, H.E. Mr. Walton Alfonso Webson, Ambassador and Permanent Representative of Antigua and Barbuda to the United Nations, and H.E. Mr. Koro Bessho, Ambassador and Permanent Representative of Japan to the United Nations, for their leadership and dedication in the fight against TB.

While this High-Level Meeting sends a strong signal that the world is finally becoming more aware of the realities of the TB epidemic, progress against it is still far too slow, and in some cases, stagnant.

With 10 million people falling ill with TB each year, and TB being the leading cause of death among people living with HIV, a drastic change in our combined approaches is desperately required to reverse these trends.

We are in urgent need of new tools to prevent, diagnose, and treat TB to meet global targets and save lives.

We must create a research-enabling environment that streamlines and expedites innovation and promotes collaboration across UN member states in order to introduce new tools to prevent, diagnose and treat TB in all its forms.

The Political Declaration symbolizes the global momentum toward our common goal of ending TB, but it is only a starting point. While a truly momentous step in the right direction, the Political Declaration reflects only the bare minimum that will be required to get ahead of the TB epidemic.

We wholeheartedly welcome the commitments outlined in the Political Declaration and we stand ready to support, advise on, monitor, evaluate and actively participate in countries' most ambitious plans to end TB.

To fully deliver on these commitments, governments must be ready to go beyond the activities outlined in the Political Declaration, which, due to the realities of reaching consensus across 193 Member States, necessarily leaves out a large number of recommendations put forward by experts, including TB affected communities, civil society and other stakeholders.

We therefore call on governments to act in the best interest of their citizens, who continue to fall ill with and die from TB at alarming rates.

In addition to the commitments currently outlined in the Political Declaration, we call on the governments of all countries present here at the UN High-Level Meeting on the Fight to End Tuberculosis to commit themselves to:

#### REACH ALL PEOPLE BY CLOSING THE GAPS ON TB DIAGNOSIS, TREATMENT, AND PREVENTION

- Diagnose and provide preventative therapy to a cumulative 80 million people by 2022 through both public and private-sector health services including 9 million children exposed to TB;
- Review and align National TB Strategic Plans based on the 2018 Political Declaration with clear national targets for TB diagnosis, treatment, prevention and care, with regular evaluation and review.

#### TRANSFORM THE TB RESPONSE TO BE EQUITABLE, RIGHTS-BASED, AND PEOPLE-CENTRED

- Go beyond removing discriminatory laws and additionally promote laws, policies, and practices with respect to right to health and access to services for people infected with and affected by TB;
- In addition to those included in the Political Declaration, make specific mention of the following key affected populations in the global and national implementation of the Political Declaration: sex workers, undocumented immigrants, people who are homeless, people who face legal barriers to access care, lesbian, gay, bisexual, or transgender people, people who are at increased risk of TB because of biological factors that compromise immune functions, and people undergoing immunosuppressive therapy;
- Facilitate equitable access and universal uptake of TB medicines, diagnostics, and vaccines through:
  - utilising public health safeguards available under the WTO Agreement on Trade Related Aspects of Intellectual Property Rights (TRIPS) including the use of compulsory licenses and public non-commercial use licenses to ensure improved access to TB medicines, diagnostics and vaccines;
  - strengthening the WHO pre-qualification system and making greater use of the WHO Collaborative Registration system to expedite national registration;
  - o facilitating and incentivising broad and expedited registration of TB medicines, diagnostics, and vaccines by originators and generic producers in TB-endemic countries.

#### ACCELERATE DEVELOPMENT OF ESSENTIAL NEW TOOLS TO END TB

- Support the development of a 2-month or less oral cure for TB and its drug resistant forms before 2028;
- Ensure that one or more new or repurposed vaccines are ready to enter the registration process for global use by 2025;
- Support the development of affordable point-of-care TB diagnostics that are non-sputum-based, can determine response to critical drugs in order to direct patients to appropriate treatments and safeguard medicines against antimicrobial resistance, and can identify individuals at high risk of progression from latent TB infection to active disease and enable targeted preventive treatment by 2025;
- Support the full spectrum of TB R&D, from basic science, to product development, to implementation research, and create regulatory and policy environments that facilitate research and the rapid uptake of new interventions;
- Ensure that all TB R&D efforts are needs-driven, evidence-based, and guided by the core principles of affordability, efficiency, equity, and collaboration;
- Work together with other governments, partners, and stakeholders to introduce innovative financing models and appropriate incentive mechanisms, including those that advance the

- concept of de-linkage by separating the costs of R&D from expected prices and sales volumes of final products;
- Increase investments toward expansion of treatment options by hastening R&D of new tools, and rolling out of latest, scientifically approved TB, MDR-TB medications that are safe to use such as Bedaquiline and Delamanid, as well as availability of nucleic acid amplification tests (such as GeneXpert machines) in all clinics and point-of-care facilities.

#### INVEST THE FUNDS NECESSARY TO END TB

- As part of the commitment to invest "appropriately" in TB R&D, spend up to or beyond 0.1% of gross domestic expenditure on R&D (GERD) on TB research to reach the global funding target of US \$2 billion for TB R&D annually;
- Provide targeted financial and technical support for countries in transition from donor to domestic financing to ensure interruptions in diagnosis, treatment and prevention do not occur and continuity of access to affordable and quality assured drugs;
- Double current investments in TB in-line with the revised estimates for the Global Plan to End TB to an average of US \$13 billion annually or US \$65 billion between 2018 and 2022.

## COMMIT TO DECISIVE AND ACCOUNTABLE GLOBAL LEADERSHIP, INCLUDING REGULAR UN REPORTING AND REVIEW

- Participate fully in the development and implementation of the WHO's multi-stakeholder accountability framework for TB;
- Support the formation of an independent review body for TB;
- As part of regional and other intergovernmental efforts on accountability, implement new monitoring tools such as scorecards and national rankings by 2020;
- Support meaningful participation by affected communities and civil society in the next UN High-Level Meeting on TB in 2023, and ensure the investment and transparency required for their meaningful engagement.

We, the undersigned members of affected communities and civil society, pledge to work with our governments, elected representatives, National TB Programmes, and all relevant stakeholders to ensure a collaborative and fully engaged approach to achieving the commitments outlined in the Political Declaration and the additional goals outlined above. We, as a global community, commit to:

- 1. Support the efforts of our governments in scaling up national responses to TB, particularly through the work of civil society organizations in engaging key populations, to ensure we find and treat all people with TB represented in the 40% of cases that go undetected;
- 2. Work alongside our governments, the World Health Organization (WHO), National TB Programmes, non-communicable diseases programmes, The Global Fund Country Coordinating Mechanisms, and all health service providers to ensure effective streamlining of service delivery and care for people infected with and affected by TB;

- 3. Hold our governments accountable to addressing the needs of key and affected populations, those most vulnerable and at risk of falling ill with TB, and to ensuring strong frameworks of support for human rights and person-centred approaches to care;
- 4. Take an active and collaborative role in the collection and analysis of data related to TB service delivery in our countries, to enable our governments to provide accurate reporting and evaluation on the progress in achieving the commitments laid out in the Political Declaration, and ensure active and appropriate engagement of key and affected populations;
- 5. Continue forging relationships between affected communities, the private sector, universities and our governments to push for stronger investments in R&D of new drugs, diagnostics, and vaccines for TB, and ensuring equitable access to life-saving drugs through de-linkage and utilization of the TRIPS flexibilities;
- 6. Continue to advocate for a fully funded Global Fund and Stop TB Partnership and hold donor governments accountable for fulfilling their pledges and commitments, while also working with multilateral funding mechanisms to ensure proper, effective use of funds that serve to best benefit the needs of people living with TB in all regions of the world.

We again wish to express our profound thanks to the co-facilitators, H.E. Mr. António Guterres Secretary-General of the United Nations, H.E. Mr. Miroslav Lajčák, President of the 72nd Session of the UN General Assembly, H.E. Ms. María Fernanda Espinosa Garcés, President of the 73<sup>rd</sup> Session of the UN General Assembly, Dr. Tedros Adhanom Ghebreyesus, Director-General of the World Health Organization, as well as Dr. Eric Goosby, UN Special Envoy on Tuberculosis, Dr. Tereza Kasaeva, Director of the World Health Organization Global Tuberculosis Programme, Dr Lucica Ditiu and all esteemed colleagues from the Stop TB Partnership, the World Health Organization, and all the community members, advocates, and healthcare providers working tirelessly around the world every day toward our common goal of ending TB.

Sincerely,

ACT AP

Action against AIDS Germany

Action Against TB Foundation (Ghana)

Action for Health Initiatives, Inc.

ACTION global health advocacy partnership

Action Santé Mondiale/ Global Health Advocates France

**ACT Nigeria** 

Aeras

Africa Japan Forum

Afrihealth Optonet Association

Aidsfonds

AIDS-Free World

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All-Ukrainian Network of PLWH

Alliance for Public Health

Alliance Pour la Santé et le Developpement Cote d'Ivoire

American Thoracic Society

Americas TB Coalition

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ASPAT PERU Asociación de Personas Afectadas por Tuberculosis del Peru

Aye Myanmar Association

Aye Nyein Metta Association

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GAT - Grupo de Ativistas em Tratamentos

GESTOS Soropositividade, Comunicação e Gênero

Global Coalition of TB Activists (GCTA)

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Japan AIDS & Society Association

Jointed Hands Welfare Organization

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