

H.E. Mr. Walton Alfonso Webson

Ambassador and Permanent Representative of Antigua and Barbuda to the United Nations

Per email / hand delivery

H.E. Mr. Koro Bessho

Ambassador and Permanent Representative of Japan to the United Nations

Per email / hand delivery

6 June 2018

Dear H.E. Mr. Walton Alfonso Webson and H.E. Mr. Koro Bessho,

Human rights are imperative to the success of the tuberculosis response

We are people affected by tuberculosis (TB), members of affected communities, civil society organizations, human rights lawyers, health care workers, and TB activists from around the world. We write to you unified in this central message: **We can end TB together, but only if we take human rights seriously.** Human rights must be both anchor and lodestar to our response at all levels.

We echo the call for “priority actions” from the Civil Society groups to transform the TB response to be equitable, rights based, and people-centered. We also note that member states have already made key commitments embodied in human rights instruments that have significant implications for the TB response, many of which require faster and bolder action of the type the upcoming United Nations High-Level Meeting—United to End Tuberculosis: an urgent global response to a global epidemic (the HLM) is meant to drive.

To this end, we look forward to the HLM. We take heart in the role you are playing to co-facilitate intergovernmental consultation and negotiation on the modalities and outcomes of the HLM.

Under your leadership, the HLM outcomes hold the potential to change the course of the global response to TB. To do this, it is imperative that the HLM results in commitments grounded in and aimed at promoting the human rights of all people affected by TB.

We welcome the Draft Elements Paper dated 25 May 2018, which proposes a preliminary draft of a political declaration that the HLM will ultimately produce. In that context, our dedication to the fight against TB and the success of the HLM compels us to highlight the below 12 key human rights commitments that, were they to be made at the HLM and then faithfully implemented, would enable the end of TB.

At the United Nations High-Level Meeting—United to End Tuberculosis: an urgent global response to a global epidemic, countries should commit to:

1. Facilitate, through legislation and policy, proactive measures that enable people affected by TB and DR-TB to lead in the formulation, implementation, and monitoring and evaluation of the TB response at all levels. Cognizant of the social and economic conditions that often impede their full engagement, such measures must include providing financial and technical support to TB community groups and civil society.
2. Prohibit in law and policy all forms of discrimination against people affected by TB – including in employment, education, housing, and health care settings – and repeal or amend any laws or policies that discriminate against people based on TB or other health status. Further, establish legal protections for the rights to privacy and confidentiality for people affected by TB, and establish accessible remedies for discrimination or violations of the rights to privacy or confidentiality.
3. Set clear, specific targets and timelines that fulfil human rights obligations arising from domestic, regional, and international law, including the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. These targets must include the full participation of civil society and affected communities, including people affected by drug-resistant TB (DR-TB), be fully resourced and implemented, and be aligned to the WHO End TB Strategy, the Stop TB Partnership Global Plan to End TB, and the Sustainable Development Goals.
4. Fulfil the right of all people to access high quality, people-centered testing and treatment services for TB and DR-TB, including new drugs and technologies, such as bedaquiline, delamanid and rapid diagnostic tests. Further, implement community-based services that are accessible to all people and take all measures necessary to reach all people in need of such services, including through the deployment of community health workers employed under dignified conditions.
5. Establish or strengthen domestic legislative and policy frameworks to align with international human rights and best practices relating to detained people, including the Nelson Mandela Rules (formerly known as the United Nations Standard Minimum Rules for the Treatment of Prisoners), with independent oversight and accountability mechanisms to ensure fulfilment of the rights of detained people. These include the rights to be provided with high quality testing and treatment services for TB and DR-TB and to conditions of detention consistent with human dignity and the prevention of TB, including proper ventilation and the absence of overcrowding.
6. Establish or strengthen national legislative and policy frameworks to ensure effective TB prevention, testing, treatment and care for migrants, including by making clear provision in law for: the right of all people, regardless of immigration status, to access TB and other health services; protections against negative immigration or other consequences when

accessing health services; and measures to promote continuity of care for mobile populations. Further, repeal or amend any laws that allow for deportation due to TB or other health status.

7. End the unnecessary use of sub-optimal medicines by updating national TB guidelines and essential medicine lists to align to WHO standards, issuing humanitarian waivers, and establishing rapid registration programs where medicines for DR-TB are not registered. Further, take proactive measures to ensure that WHO guidelines are rapidly updated to provide clear and evidence-based guidance that takes into account the debilitating impact of severe treatment side-effects such as hearing loss.
8. Fulfil the core human right of access to existing treatments through implementing the recommendations of the United Nation Secretary-General's High-Level Panel on Access to Medicines, including the recommendations that:
 - 8.1. World Trade Organization (WTO) Members "must make full use of the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) flexibilities as confirmed by the Doha Declaration to promote access to health technologies when necessary";
 - 8.2. States should "adopt and implement legislation that facilitates the issuance of compulsory licenses"; and
 - 8.3. States should, through a process initiated by the United Nations Secretary-General, urgently establish a "binding R&D Convention that delinks the costs of research and development from end prices to promote access to good health for all."
9. To address the need for development of new medicines required to fulfil the right to health, fill the US\$1.3 billion annual funding gap for TB research and development, including by dedicating at minimum 0.1% of national expenditure on research and development to innovations related to the TB response, and ensure that the products of such public investment are available and affordable to all who need them.
10. Ensure local and national accountability by funding civil society organizations that work to protect and promote human rights. Further, fund, and otherwise support, local accountability structures such as clinic and village health committees, including by adopting legal and policy frameworks that promote their operations and ensure their independence.
11. Identify populations most affected by TB and develop systems to monitor progress in the TB response among these populations, including through improved disaggregated data, while ensuring protection of their right to privacy and confidentiality.
12. Double current funding to US\$13 billion annually in order to reach the global targets established in the WHO End TB Strategy and the Stop TB Partnership's Global Plan to End TB 2016-2020.

Conclusion

These commitments to specific law and policy reform for human rights are prerequisites to the success of all other commitments that might be made at the HLM. We are hopeful that you will engage these imperatives, incorporate them into the consultation and negotiation process, and advocate for their inclusion in the outcomes of the HLM.

We invite the wide distribution of this letter as you in your good judgment see fit. We also respectfully request an opportunity to engage directly with you on progress toward a political declaration that marks a turning point for the TB response. We eagerly await correspondence indicating your earliest convenient availability for such an engagement.

We are committed to the success of the HLM and to supporting you in your efforts toward that end. We submit this correspondence, and hope it will be received, in that spirit.

We request that you kindly confirm receipt.

Yours in solidarity in the fight to end TB,

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Signatories:

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3. Access to Rights and Knowledge Foundation, India
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10. Afrihealth Optonet Association
11. AIDS Accountability International
12. AIDS Action foundation
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14. AIDS and Rights Alliance for Southern Africa (ARASA)
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16. AIDS-Free World
17. Allan Maleche
18. Alliance for Public Health (Ukraine)
19. APCASO
20. Arumugam Sankar
21. Asociación Nacional de Personas Positivas Vida Nueva de El Salvador
22. Association for Reproductive and Family Health (ARFH)
23. Association Marocaine de Solidarité et de Développement (AMSED)
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47. Club des Amis Damien
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68. Dr. Pramila Singh
69. East African Harm Reduction Network (EAHRN)
70. Eastern Africa National Networks of AIDS Service (EANNASO)
71. Education For Self Help (ESEH)
72. EKPIZO, Consumer Association the Quality of Life
73. Empower India

74. Esther Nelima
75. Eurasian Network of People who Use Drugs (ENPUD)
76. Eva Limachi Salgueiro
77. Ever Mvera
78. Exodus
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91. Global TB Community Advisory Board (TB CAB)
92. Global Network of People Living with HIV (GNP+)
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95. Genesis Support Group

96. Grupo de Ativistas em Tratamentos (GAT)
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98. Health Action International (HAI)
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101. HIV/AIDS People Alliance of Kenya, HAPA Kenya
102. HIV Justice Network
103. Hope Support Group
104. Ida Léa Savadogo/Yugbare
105. India HIV/AIDS Alliance
106. Initiative for Health and Equity in Society
107. Instituto de Salud Msc Cristóforis Deneke (ISDEN)
108. Interagency Coalition no AIDS and Development (ICAD)
109. International AIDS Society
110. International Community of Women Living with HIV
111. International Indigenous HIV & AIDS Community (IIHAC)
112. International Network of People who use Drugs (INPUD)
113. Jane Side
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115. Jointed Hands Welfare Organisation (JHWO)
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117. Jonathan Stillo

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120. Joyce Tandi Munala
121. KELIN
122. Kenya AIDS NGO Consortium (KANCO)
123. Kenya Treatment Access Movement- KETAM
124. Khairunisa Suleiman
125. KHANA-Cambodia
126. Kilifi Youth Bunge
127. Kikamba Arts Expert Arts Youth Group
128. Kisumu Ndogo Initiative
129. Kigali Hope
130. Lawyers Collective
131. Lean on Me Foundation
132. Lesley Odendal
133. LHL International Tuberculosis Foundation
134. Linda RM Baumann
135. Linda Wanjiru Kroeger
136. Lindsay McKenna
137. Lloyd N. Friedman
138. Lucy Ghati
139. Ludmila Cristina do Carmo Tavares

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141. Malawi Women's Coalition Against Cancer
142. Marcus Low
143. Maria van der Linde
144. Marilynne Laini
145. Mary Mwanaidi
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147. Maxime Lunga
148. Merlin Young
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150. Michael Akanji
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152. Mwanakombo Said
153. Muhumuza Abdulkharim
154. Masika Khamisi
155. Mtwapa Youth Group
156. Mujjaheed in Support Group
157. Mwanhawa Chai
158. Mwavitendo Support Group
159. Namibia Diverse Women's Association (NDWA)
160. Midii Bakari
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162. Nana Gleeson, BONELA
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164. Naomi Monda
165. Network of people living with HIV/AIDS in Kenya (NEPHAK)
166. Nkoko Iju Africa
167. Nawiri Adolescent Parent Youth Group
168. Observatório Tuberculose Brasil
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170. Olga Leones, representante legal de la Corporación Pazaporte
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172. Organizaciones Sociales de la Comunidad ante el Comité Nacional de Prioridades
173. Owomugisha Immaculate
174. Pamoja TB group
175. Pan African Positive Women's Coalition-Zimbabwe
176. Paneer HIV Women Network Trust
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190. Said Geneso Youth Group
191. Susan Ongechi
192. Safe Community Youth Initiative
193. Salud por Derecho
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196. See Change Initiative
197. Sofia Gruskin
198. Shine Us
199. Stephen Lewis
200. STOPAIDS
201. STOP TB PARTNERSHIP, Kenya
202. Suraj Mandoori
203. TB People
204. TB Proof
205. Timur Abdullaev

206. Tororo Forum for People Living with HIV Networks (TOFPHANET)
207. Treatment Action Campaign
208. Treatment Action Group
209. Tumaini Young Mothers
210. Takaungu Support Group
211. Terry Dama
212. Uwezo Support Group
213. Uganda Harm Reduction Network(UHRN)
214. Uganda Network on Law, Ethics and HIV/AIDS(UGANET)
215. Ukrainian Network of People Who Use Drugs
216. Umoja Support Group
217. Victory Post Test Group
218. Warembo Forum
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222. Wim Vandavelde
223. Women-Concern Liberia
224. Wote Youth Development Projects
225. Yolse, Santé Publique & Innovation
226. Youth LEAD
227. Zimbabwe Civil Liberties and Drug Network