

My patient's choice - the Jolene Samuels MDR-TB Pledge

A carer's pledge to offer patients an informed choice between a novel drug or an injectable drug for the treatment of MDR-TB

~ In loving memory of nurse [Jolene Samuels](https://vimeo.com/103717862) (<https://vimeo.com/103717862>), MDR-TB Champion & Cochlear Implant recipient ~

I, the undersigned, am involved in the direct and/or indirect care of people with MDR-TB (multidrug-resistant tuberculosis). I hereby pledge to empower the people I care for to choose between the use of a novel drug (currently bedaquiline or delamanid) or an injectable aminoglycoside drug as part of their MDR-TB regimen, based on all relevant information about known benefits and risks shared with them.

I acknowledge that there are current data limitations, but in my opinion there is enough information to reasonably assume that MDR-TB regimens with a novel drug are at least equally effective compared to the old MDR-TB regimen containing an injectable during the intensive phase of treatment. Based on all available information, as summarised in a recent review by [Reuter et al](#), both current novel drugs likely result in fewer serious adverse events than the injectables, particularly debilitating irreversible ones such as hearing loss, which may occur in as many as half of people treated with injectables for MDR-TB. I am also aware that an individual patient data meta-analysis of 9153 patients from 32 observational studies with MDR-TB in 2012 by [Ahuja et al](#) found no association between the use of any injectable agent and the probability of treatment success. Furthermore, in the new shorter MDR-TB treatment course of nine months the injectable agent has been replaced by bedaquiline for all pregnant patients in the Western Cape Province of South Africa, and injectable-free regimens have been recommended by the WHO for some children who are living with MDR-TB.

There are a number of clinical trials currently being done to formally assess the efficacy and safety of injectable free regimens, but the results of these studies are likely to take several years to become available. Given the limited evidence to support the efficacy of injectable agents and the clearly documented safety risks they pose, I believe that persons living with MDR-TB should be offered treatment options that would allow them to avoid the use of injectable agents in their treatment plan, while simultaneously according them the right to enjoy the benefits of scientific progress. ([London et al](#), 2016)

I therefore commit to giving every person diagnosed with MDR-TB under my care the opportunity to choose whether they would prefer to be treated with an MDR-TB regimen that contains a novel agent (either bedaquiline or delamanid) or one that contains an injectable agent. In settings where novel drugs are not yet available, I will ensure my patients can take part in shared decision making about their care and I will support their calls for access to safer and more effective alternatives.

Anybody involved in the direct or indirect care of people with TB is most welcome to sign on, in person or via the web link: <http://www.tbproof.org/pledge>

After signing, please consider circulating the link via email and/or social media, using the hashtag: [#MyPatientsChoice](#)

For more information or if you would like to get more involved, please email ingrid.tbproof@gmail.com

My patient's choice pledge – signatories to date (21 March 2018):

Organisations:

1. ACTION global health advocacy partnership
2. Advocates for Health and Development Initiative
3. DR-TB STAT
4. Grassroots Development and Empowerment Foundation
5. Management Sciences for Health
6. Mongolian TB Coalition
7. REDTBAC
8. RESULTS International Australia
9. Sentinel Project on Pediatric Drug-Resistant TB
10. Socios en Salud Sucursal Peru
11. TB HIV Care
12. TB Proof
13. Treatment Action Group

Individuals and designation/s:

1. Zumla, Sir Alimuddin - Academic/technical expert/research field
2. Adams, Cady - Healthcare worker
3. Adrei, Dadu
4. Adriaanse, Shabirah - Healthcare worker
5. Anamaria Cardenas, Javier Pablo
6. Arago Galindo, Miriam - Healthcare worker
7. August, Mavo - Healthcare worker
8. Barnard, Aleche - Healthcare worker
9. Barry, Mo - Academic/technical expert/research field
10. Bechir, Ndaw - Other care provider
11. Bekker, Arlette - Healthcare worker
12. Berrie, Leigh - Other care provider
13. Binlayan, Maria Elena
14. Brigden, Grania - Healthcare worker
15. Britt, Pam
16. Caldwell, Judy - Healthcare worker
17. Cariem, Rabia - Healthcare worker
18. Carnero Avendaño, Margeory Alexandra - Civil Society/Advocacy
19. Carrillo Montenegro, Vanessa - Media
20. Cassidy, Tali - Academic/technical expert/research field
21. Charalombous, Salome - Other care provider
22. Chavan, Nishant - Academic/technical expert/research field
23. Chiganze, Khanyisile - Academic/technical expert/research field
24. Chimuka, Hameline - Other care provider, Civil Society/Advocacy
25. Churchyard, Gavin - Academic/technical expert/research field
26. Cindi, Lindelwa - Healthcare worker
27. Cookson, Susan - Healthcare worker
28. Crouch, Skye - Healthcare worker
29. Cruzado, Lourdes - Healthcare worker, Civil Society/Advocacy

30. da Silva Telles, Maria Alice
31. Damse, Ziyanda - Healthcare worker
32. Daniels, Colleen - Policy maker/management
33. De Staalo, Janet - Healthcare worker
34. Dharmaraj, Daisy - Healthcare worker
35. Ditiu, Lucica - Healthcare worker, Policy maker/management, Academic/technical expert/research field
36. Dolby, Tania - Healthcare worker
37. Domenti, Oxana - Policy maker/management
38. Dramowski, Angela - Healthcare worker, Person affected by TB, Civil Society/Advocacy, Academic/technical expert/research field
39. Duncan, Kristal - Academic/technical expert/research field
40. Ekanoye, Kolawole - Other care provider, Civil Society/Advocacy
41. Ferlazzo, Gabriella - Academic/technical expert/research field
42. Forster, Faudia - Civil Society/Advocacy
43. Galloway, Michelle - Civil Society/Advocacy
44. Garcia, Fanny - Healthcare worker
45. Gardner, Lynn - Healthcare worker
46. George, Lisa - Svahn - Healthcare worker
47. Gerstenhaber, Rodd - Civil Society/Advocacy
48. Gichane, Waru - Academic/technical expert/research field
49. Gunst, Colette - Healthcare worker
50. Gunturu, Revathi - Healthcare worker
51. Gweja, Sindiswe - Healthcare worker
52. Hanson-Nortey, Nii Nortey - Policy maker/management
53. Haridus, Neesha - Other care provider, Civil Society/Advocacy
54. Heap, Marion - Academic/technical expert/research field
55. Herrera, Rosa - Healthcare worker
56. Horn, Liana - Healthcare worker
57. Human, Wieda - Healthcare worker, Civil Society/Advocacy
58. Huysen, Karin - Healthcare worker
59. Islam, Zahedul - Policy maker/management
60. Jankelowitz, Lauren - Policy maker/management, Civil Society/Advocacy
61. Jantjie, Nthabeleng - Healthcare worker
62. Joseph, Ashton - Healthcare worker
63. Kalawe, Nosi - Healthcare worker, Policy maker/management, Civil Society/Advocacy
64. Kapanda, Max - Other care provider
65. Kekana, Adelaide - Healthcare worker
66. Kekana, Lerato - Healthcare worker
67. Kelly, Amber - Academic/technical expert/research field
68. Kizilbash, Quratulain - Healthcare worker
69. Klinkenberg, Eveline - Academic/technical expert/research field
70. Komane, Robert - Healthcare worker
71. Kotze, Koot - Healthcare worker, Civil Society/Advocacy
72. Kotze, Maritsa - Healthcare worker
73. Kutadza, Tariro - Civil Society/Advocacy
74. Laniado- Laborin, Rafael - Healthcare worker
75. Larisa, Soroaga - Healthcare worker, Academic/technical expert/research field
76. Lewis, Lydia - Healthcare worker
77. Lochner, Jeanette - Person affected by TB

78. Madsen, Ena - Policy maker/management
79. Mafongosi, Nandipa - Academic/technical expert/research field
80. Makanda, Goodman - Other care provider, Civil Society/Advocacy
81. Martin, Delene - Person affected by TB
82. Master, Iqbal - Healthcare worker
83. Matiting, Kagiso Norman - Person affected by TB, Civil Society/Advocacy
84. Matthews, Margaret - Healthcare worker, Person affected by TB
85. Meis, Max - Healthcare worker
86. Mendoza, Milagros - Healthcare worker
87. Miller, Mary - Healthcare worker
88. Millones, Ana - Healthcare worker
89. Misra, Nirupa - Healthcare worker
90. Mkhondo, Nkateko - Academic/technical expert/research field
91. Mohanty, Subrat - Civil Society/Advocacy
92. Mohr, Erika - Academic/technical expert/research field
93. Mondi, Dipela - Civil Society/Advocacy
94. Moran, Carolina - Civil Society/Advocacy, Academic/technical expert/research field
95. Morta, Juwaya - Healthcare worker
96. Mosidi, Thato - Healthcare worker, Person affected by TB, Civil Society/Advocacy
97. Mpambane, Usiphe - Other care provider
98. Msimang, Busi - Other care provider, Academic/technical expert/research field
99. Mthebe, Thami - Healthcare worker
100. Mutsvangwa, Tinashe - Academic/technical expert/research field
101. Muzenda, Glenda - Civil Society/Advocacy, Academic/technical expert/research field
102. Naicker, Chenise - Healthcare worker
103. Naidoo, Lenny - Healthcare worker, Policy maker/management, Civil Society/Advocacy
104. Naidoo, Pren - Academic/technical expert/research field
105. Namutamba, Dorothy - Civil Society/Advocacy
106. Naomi, Wanjiru - Healthcare worker, Person affected by TB, Civil Society/Advocacy
107. Narotam, Heena - Healthcare worker
108. Nathavitharana, Ruvandhi - Healthcare worker, Civil Society/Advocacy,
Academic/technical expert/research field
109. Ndjeka, Norbert - Policy maker/management
110. Nelson, Aurelie - Healthcare worker
111. Ngambu, Noluvo - Healthcare worker
112. Nilsson, Caroline - Healthcare worker
113. Okada, Kosuke - Academic/technical expert/research field
114. Patac, Eduardo - Person affected by TB
115. Patil, Raghavendra - Healthcare worker
116. Penaredondo, Ronald Armando - Person affected by TB, Civil Society/Advocacy
117. Perea, Sara - Healthcare worker, Academic/technical expert/research field
118. Peters, Jurgens - Healthcare worker, Academic/technical expert/research field
119. Peters, Shrikant - Healthcare worker
120. Pezisa, Norah - Healthcare worker
121. Plaatjie, Nontle - Healthcare worker
122. Plaatjies, Charletie - Healthcare worker
123. Prem, Prakash Anand - Academic/technical expert/research field
124. Puma Abarca, Daniela
125. Ramos Carhuas, Karen Edith - Healthcare worker
126. Rangana, Noma - Civil Society/Advocacy

127. Raw, Felicity - Healthcare worker
128. Reddy, Mogie - Academic/technical expert/research field
129. Redman, Romany - Healthcare worker
130. Rodriguez, Carly - Academic/technical expert/research field
131. Romero, Rodolfo - Healthcare worker
132. Rosser, Andrew - Healthcare worker
133. Roy, Mike - Other care provider, Civil Society/Advocacy
134. Rumaldo, Haydee - Healthcare worker
135. Rushwaya, Rue - Other care provider
136. Rutanga, Claude - Academic/technical expert/research field
137. Samsodien, Faieka - Healthcare worker
138. Sauk, Joyce - Healthcare worker
139. Schoeman, Ingrid - Healthcare worker, Person affected by TB, Civil Society/Advocacy
140. Schuetzenberger, Sebastian - Healthcare worker, Academic/technical expert/research field
141. Seaworth, Barbara
142. Seddon, James - Healthcare worker, Academic/technical expert/research field
143. Sifube, Mavis - Healthcare worker
144. Sifumba, Zolelwa - Healthcare worker, Person affected by TB, Civil Society/Advocacy
145. Slutsker, Mandy - Civil Society/Advocacy
146. Snyders, Bonnie - Healthcare worker
147. Sonamzi, Esther - Civil Society/Advocacy, Person affected by TB
148. Sonnenberg, Megan - Policy maker/management
149. Stander, Elana - Healthcare worker, Person affected by TB
150. Stickers, Beatrijs - Civil Society/Advocacy
151. Stuttaford, Maria
152. Thakur, Rahul - Academic/technical expert/research field
153. Theron, Marianna - Healthcare worker
154. Thompson, Mary - Healthcare worker
155. Tisile, Phumeza - Civil Society/Advocacy
156. Titi, Nondwe - Civil Society/Advocacy
157. Tolossa, Wubshet Jote - Healthcare worker, Person affected by TB, Civil Society/Advocacy
158. Tommasi, Marcela - Healthcare worker
159. Trafford, Zara - Academic/technical expert/research field
160. Tshabalala, Sibongile - Civil Society/Advocacy
161. Turner, Karin - Policy maker/management
162. Ustero Alonso, Pilar - Healthcare worker
163. Van Breda, Emma - Healthcare worker
164. Van Der Lingen, Warick - Healthcare worker
165. van der Westhuizen, Ananja - Civil Society/Advocacy
166. van der Westhuizen, Helene-Mari - Healthcare worker, Person affected by TB, Civil Society/Advocacy, Academic/technical expert/research field
167. Van Zyl, André - Academic/technical expert/research field
168. van Zyl, Christel - Healthcare worker
169. van Zyl, Rita - Healthcare worker
170. Variava, Ebrahim - Healthcare worker, Academic/technical expert/research field
171. Vatsyayan, Vindhya - Academic/technical expert/research field
172. Venter, Francois - Healthcare worker, Policy maker/management
173. von Delft, Andrea - Healthcare worker, Person affected by TB, Civil Society/Advocacy

174. von Delft, Arne - Healthcare worker, Person affected by TB, Civil Society/Advocacy, Academic/technical expert/research field
 175. von Delft, Dalene - Healthcare worker, Person affected by TB, Civil Society/Advocacy,
 176. von Delft, Dirk - Healthcare worker
 177. Wanjiru, Naomi - Healthcare worker, Person affected by TB, Civil Society/Advocacy
 178. Wares, Fraser - Healthcare worker
 179. Willems, Bart - Healthcare worker, Person affected by TB, Civil Society/Advocacy, Academic/technical expert/research field
 180. Williams, Abeda - Other care provider
 181. Wilson, Teresa - Healthcare worker
 182. Wright, Glenda - Healthcare worker
 183. Wydeman, Nicolien - Healthcare worker
 184. Yataco, Rosa - Healthcare worker
 185. Yawa, Anele - Civil Society/Advocacy
 186. Yisa, Barnabas - Other care provider
 187. Zangmo, Kinley
 188. Zweigenthal, Virginia - Academic/technical expert/research field
-