**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


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 Furthermore, in the new shorter MDR-TB treatment course of nine months the injectable agent has been replaced by bedaquiline for all pregnant patients in the Western Cape Province of South Africa, and injectable-free regimens have been recommended by the WHO for some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](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](mailto:ingrid.tbproof@gmail.com)

#MyPatientsChoice Pledge
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. REDTBLAC
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:
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28. Crouch, Skye - Healthcare worker
29. Cruzado, Lourdes - Healthcare worker, Civil Society/Advocacy

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30. da Silva Telles, Maria Alice - Healthcare worker
31. Damse, Ziyanda - Healthcare worker, Policy maker/management
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. Domeniti, Oxana - Policy maker/management
38. Dramowski, Angela - Healthcare worker, Person affected by TB, Civil Society/Advocacy, Academic/technical expert/research field
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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. Hom, Liana - Healthcare worker
57. Human, Wieda - Healthcare worker, Civil Society/Advocacy
58. Huyssex, Karin - Healthcare worker
59. Islam, Zahedul - Policy maker/management
60. Jankelowitz, Lauren - Policy maker/management, Civil Society/Advocacy
61. Jantjie, Nthabeleng - 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

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<tr>
<th>No.</th>
<th>Name</th>
<th>Position / Role</th>
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169. van Zyl, Rita - Healthcare worker
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175. von Delft, Dalene - Healthcare worker, Person affected by TB, Civil Society/Advocacy
176. von Delft, Dirk - Healthcare worker
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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
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