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OPEN LETTER:

To: Dr Aaron Motsoaledi, South African Minister of Health

18 June 2018

Not deaf or dead - a third choice for all with drug-resistant TB, thank you!

Dear Dr Motsoaledi, our tireless TB Champion

We would like to congratulate you and your terrific TB team with the **exceptional improvements in drug-resistant tuberculosis (DR-TB) treatment outcomes and the thousands of lives saved** through your world leading expanded access to bedaquiline! (1) This represents a major victory in the shared battle to end all forms of TB and related suffering. And today you have set the bar even higher with the release of the Department of Health statement announcing that an **injectable-free regimen will be recommended to all patients with rifampicin-resistant TB in South Africa.**

Seven years ago Dr Dalene von Delft was given a choice that thousands of people with MDR-TB have faced before, “**Deaf or Dead?**” (Image 1) “As a doctor, I couldn’t believe those were my only options, so I asked for a second opinion, but got the same answer.” She kept asking for a third choice and was extremely lucky to find it on 8 July 2011, when she became the first person with MDR-TB ever to receive compassionate access to bedaquiline to replace the damaging injectable drug. It saved her hearing and career, and possibly also her life. (2,3) Barely a year later, Dr Thato Mosidi became one of the first recipients of an **entirely injectable free DR-TB regimen containing bedaquiline and linezolid**, as part of the prescient expanded Bedaquiline Clinical Access Programme (BCAP). (4)

In closing the South African TB Conference on Friday you offered more proof that our world leading access programmes to new TB drugs truly are ‘**game changers**’, with a **remarkable 16.7% increase in DR-TB treatment success** (or one out of every six patients treated) and **9% decrease in mortality**



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whenever bedaquiline was added. These findings are consistent with the published literature (5–10) and **civil society’s repeated call that bedaquiline be made available to everybody with MDR-TB to replace the toxic and painful injectable drugs.** (11–14) In the face of such exemplary progress there can no longer be any justification for the continued use of injections, which **cause irreversible hearing loss in up to half of all people who receive them,** especially when there is still such limited evidence that they are effective? (15)

To quote another courageous DR-TB survivor, Phumeza Tisile, who lost her hearing entirely, only to find out afterwards that the offending injection had not even worked: “I wouldn’t wish anyone to go through what I went through with drug-resistant TB. The drugs alone are a nightmare; **becoming deaf because of a drug’s side effects is life-destroying.**” (16)

As a community of TB survivors, care providers and activists we are dismayed that so many people, like Phumeza, are still asked to **choose between their hearing or their life when there is a safer and more effective drug available.** Especially considering that Dalene was given a third choice seven years ago already. And knowing that people with extensively drug-resistant (XDR-) TB, like Thato, now have higher cure rates than people with MDR-TB, because they have routine access to injectable free regimens containing bedaquiline, linezolid and, increasingly, delamanid.

Vice-president David Mabuza reiterated on 13 June that “**Nobody should needlessly die, and definitely, not from TB.**” (17) The fact that two thirds of all people to have accessed bedaquiline live in South Africa is testament to our government’s commitment to Batho Phele: putting the people and their rights first. We are thrilled that President Ramaphosa will lead the formidable South African delegation to the landmark [United Nations General Assembly High-level Meeting on ending TB](#) (UN HLM) in September. We are also delighted that you agreed in principle with civil society’s key asks, (18) as handed over to you by Dr Zolelwa Sifumba, another occupational MDR-TB survivor who had to suffer through excruciating daily injections. (19) To echo her words, and those of Thato who preceded her on the stage, and Phumeza and Dalene, and all those for whom they speak: **there could be no bolder and stronger signal of shared intent than by replacing the injectables with bedaquiline,** thereby giving every South African with MDR-TB a **priceless third choice!**

And today you heeded our collective call, thank you!

We are ecstatic that no South African with this terrible disease will have to ‘choose’ between their hearing or their life again. This is an evidence-based decision. This is a person-centered decision. It is **visionary and courageous and marks a fundamental shift** in how leaders and policy makers engage with people who have TB. We salute you, Minister Motsoaledi, and your fantastic team of leaders and experts. We hope that this ground breaking policy change will herald continued commitment to ensuring all patients have rapid access to drug sensitivity testing (DST) and fully effective regimens including other new and repurposed drugs, such as delamanid and linezolid. We look forward to ending all forms of TB with you!

With sincere appreciation and respect!

Signed:

TB Proof, Cape Town, 18 June 2018

The following DR-TB Survivors have made themselves available for interviews:

Dr Dalene von Delft (Occupational MDR-TB Survivor)

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Dr Thato Mosidi (Occupational XDR-TB Survivor)

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Phumeza Tisile (XDR-TB Survivor and cochlear implant recipient)

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Dr Zolelwa Sifumba (Occupational MDR-TB Survivor)

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Sr Pat Bond (Occupational MDR-TB Survivor)

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Goodman Makanda (XDR-TB Survivor)

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Dr Arlette Bekker (Occupational MDR-TB Survivor)

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Image 1: Occupational DR-TB Champions (left – right): Nurses Patricia Bond and Jolene Samuels, both of whom suffered injectable-related hearing loss, and Drs Thato Mosidi and Dalene von Delft, both of whom received hearing- and career-saving access to bedaquiline. The [#MyPatientsChoice](#) Pledge, calling for the replacement of injectables with new drugs, was named in the brave memory of Jolene, a cochlear implant recipient, who tragically passed away last year. (11) ©TB Proof

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