

# TEST ME, TREAT ME

## A DRUG-RESISTANT TB MANIFESTO

**We, the people infected with drug-resistant tuberculosis (DR-TB), live in every part of the world.**

Most of us were exposed and became infected with DR-TB because of the poor conditions in which we live. Undiagnosed, this disease spreads among us. Untreated, this disease kills. But in the countries in which we live, fast and accurate diagnosis is rarely available and only about one in five of us actually receive effective DR-TB treatment.

Those of us “lucky” enough to receive treatment have to go through an excruciating two-year journey where we must swallow up to 20 pills a day and receive a painful injection every day for the first 8 months, making it hard to sit or even lie down. For many of us, the treatment makes us feel sicker than the disease itself, as it causes nausea, body aches and rashes. The drugs make many of us go deaf permanently and some of us develop psychosis.

For most of us, life as we knew it changes dramatically. We cannot go to work, or take care of our loved ones, or go to school. Often, we are stigmatised and face social exclusion.

Surviving this treatment itself is a huge challenge – one that many people cannot manage. But we have no choice if we want to live. So we must be brave, strong-willed and have hope that we will be cured. We need immense support from our medical staff, our family and our friends to help us complete our treatment.

And even then, only half of us are successfully treated with the current drug regimens. For every person with DR-TB who signs this manifesto, there is another person who is no longer able to. The demands we make in this manifesto are therefore made in honour of their memory.

**We, the medical staff who provide medical care for people with DR-TB,** find it unacceptable that the only treatment options that we can offer people cause so much suffering, especially when the chance of cure is so low. We have no choice but to juggle combinations of largely ineffective and toxic drugs, while doing our best to manage the debilitating side effects and provide as much support and counselling as possible with limited resources.

As the epidemic continues to spread, DR-TB becomes increasingly hard to tackle. The treatment is too long, too toxic and too costly – the drugs alone cost at least \$4,000 just to treat one person. We want to save many more lives, but we desperately need shorter, safer and more effective treatment to do so.

**We, the undersigned people with DR-TB and those involved in their care, here raise the alarm about the devastating toll this disease is taking on us, our families and communities across the globe and therefore make the following three demands:**

## **1) We call for universal access to DR-TB diagnosis and treatment now:**

Governments everywhere should provide national treatment programmes to diagnose and treat all people with DR-TB. Fast and reliable diagnostic techniques should be made widely available so that DR-TB can be detected early and treatment started as soon as possible to improve our chances of cure, while reducing the risk of further transmission in our communities. Treatment and prevention measures should be available close to where people live and work so that we can continue to support our families and communities without placing them at risk or compromising our treatment. People close to us should be offered routine TB screening,

especially our children, to ensure they get necessary treatment or prophylaxis and if necessary, for our children to be treated close to home and not far away in specialist hospitals. We ask for ourselves and our families to be educated and supported through adequate counselling and to be more involved in decisions regarding our treatment. Healthcare staff should be trained to manage DR-TB within existing TB programmes at a local primary care level, so that DR-TB testing, treatment and ongoing care is accessible to as many people as possible and as close to their homes as possible.

## **2) We call for better treatment regimens - the TB research community, including research institutes and drug companies, must urgently deliver effective, more tolerable, shorter and affordable DR-TB drug regimens:**

With two new drugs for TB becoming available in 2013 and more in development, we demand that the opportunity be seized by the global TB community to urgently develop improved treatment regimens for DR-TB. We need drug regimens that are more effective against DR-TB to improve our chances of survival and reduce the horrible side effects we currently endure. We need treatment that is far shorter and does not put our lives on hold for up to two years. We need treatment that is easy to take, with fewer pills and no more painful daily

injections. We need new drug formulations, like syrups or smaller tablets, that our children with DR-TB can easily swallow. We need DR-TB drugs which do not interact with HIV medicines and which allow both diseases to be treated effectively. We need drug companies to make existing DR-TB treatment as well as newly-developed drugs available at affordable prices in countries with the greatest burden of disease to ensure those most affected are able to access effective treatment.

## **3) We call for more financial support to increase DR-TB treatment, and a commitment to support research into developing better treatment:**

International donors and governments of affected countries must prioritise and financially support diagnosis and treatment of DR-TB, through national programs, bilateral aid programs or multilateral programs like the Global Fund. New drugs must be developed specifically to treat DR-TB, while research must continue into combinations using

new and existing drugs to respond to the wide range of drug resistance. Research and development must be financed to rapidly develop not only effective and safe new drugs, but also easy-to-use, accurate and affordable diagnostics, as well as development of a vaccine to prevent the spread of TB.

## **We as patients and healthcare providers commit ourselves to:**

- Encouraging each other to test for TB, take our treatment and remain in care
- Protecting those people close to us from TB transmission
- Holding our governments accountable and pushing them to respond to the crisis
- Sharing our stories to improve TB awareness and reduce stigma in our communities

**Learn more at [www.msfacecess.org/TBmanifesto](http://www.msfacecess.org/TBmanifesto)**