

## SPECIAL REPORT

# Harrowing tale of first XDR-TB victim in Kenya

As globe gears for World TB Day tomorrow, Wangeci joins celebration as beacon of hope for beating the most extreme version of disease

by Betty Muindi  
@PeopleDailyKe

I remember the doctors at the clinic were mad accusing me of not taking my medication as pre-

Elizabeth Wangeci is a picture of perfect health. As she cuddles her three-month-old baby Paul Muriigi, his sibling John Machira playful tickles him in Toll area, Ruiru.

It is difficult to imagine that just four years ago, she is a woman who had lost all hope in life. Wangeci, a mother of three, was the first patient to be diagnosed with Extensively Drug Resistant TB (XDR-TB) in Kenya.

This is a rare type of multidrug-resistant tuberculosis (MDR-TB) on which two of the most powerful first-line anti-TB medication; *isoniazid* and *rifampin*, plus any *fluoroquinolone* and at least one of three injectable second-line drugs such as *amikacin*, *kanamycin*, or *capreomycin* are ineffective against.

"I was a Class Two and Three teacher at Stellarm Elite school in Mathare North slum and one day, I woke up with flu symptoms. I did not think much of it and assumed it was a result of inhaling too much chalk dust in class and it would go away, but it never did," she says.

When the flu persisted, this time with severe sore throat, she resorted to over-the-counter medicine.

But the condition worsened.

She went to hospital and demanded to have a TB test done but the doctor at Mathare North City Council hospital said she did not display any symptoms of a TB patient and prescribed antihistamines.

"I did not get better. I started losing weight; my complexion changed to a lighter shade and the cough was uncontrollable. My boss, told me to take days off and get myself properly checked," she reminisces.

When she went back to the hospital, Wangeci demanded that they do a TB test. They did, and the results were positive. She was put on medication for several months. Nothing changed.

"I remember the doctors at the clinic were angry and accused me of not taking my medication as prescribed, but as a teacher, and knowing what I was suffering from, I could not afford to skip a single tablet," she says.

A doctor at Kenyatta National Hospital referred her to *Medecins Sans Frontieres* (MSF), an international medical humanitarian organisation. Another test revealed she had MDR-TB.

She had to abandon her six-year teaching career to concentrate on treatment. After several months of medication, she had not improved, and her condition moved to the third and most critical level, XDR-TB.

This strain of TB could arise from improper use of antibiotics, including use of improper treatment regimens or improper dos-

## TB THEME

This year's World TB Day theme for Kenya is Mulika TB Maliza TB, ni jukumu langu coincides with the global theme, Wanted Leaders for TB free world, you can make history and end TB.

The programme intends to encourage TB prevention and occurrences as the disease remains a top 10 killer in Kenya, according to National TB, leprosy and Lung Disease Programme.

age which could include failure to complete treatment, or transmission of this strain of TB through inhalation of the bacteria according to World Health Organisation (WHO). This new borderline strain of TB had not been diagnosed on anyone else in the country before.

After days of research, *Doctors Without Borders* at MSF administered Bedaquiline, a new experimental drug, combined with other conventional TB medicines.

Her son, Machira, who was then two-year-old, exhibited symptoms of XDR-TB as well, which compelled the doctors to also put him to half-dose treatment.

"I was advised to bring my son for screening and he too turned positive. He was weak but after taking the medication for six months, he got better," she said.

But her situation was not improving despite going to the clinic every morning to get an injection and pills for six months.

Besides, the drugs had serious side effects. She felt weak, ex-



Wangeci with her sons Machira and Muriigi. BOTTOM: infectious diseases specialist with Doctors Without Borders Hussein Kerrow. PHOTOS GERALD ITHANA AND SANDRA WEKESA.

tremely cold and sickly. Her skin complexion became dark and she could barely walk.

"I was giving up. The 13 pills I took daily always stuck in my throat and threatened to come out. I was tempted to stop them, after all, I was not getting better and some patients I knew had passed on. But doctors at the clinic, family and friends encouraged me to continue with the treatment," she says.

Her son on the other hand was also affected by the strong medication delaying his milestones.

Wangeci is glad that eventually, she started improving and at some point the injections stopped. She completed taking her medication

in June 2016 and her health has improved since then.

Today, two years after receiving a clean bill of health, Wangeci and her son are as fit as a fiddle.

She is grateful to the government for the incentives she was given during the times she was on treatment.

"We received Sh12,000 every month allowance to help take care of ourselves and also facilitate our journeys to hospital every morning for medication," she said.

As the world celebrates World TB Day tomorrow, Wangeci stands as a beacon of hope that one day, Kenya will be free of the debilitating disease.

## Team of young people use technology to



The team at Keheala that is using technology to ensure patients adhere to TB medication routine. PHOTO: COURTESY

by Rebeca Mutiso  
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A one-roomed office with minimalist décor in Nairobi's city centre houses a team of seven people working relentlessly to save the lives of people infected with tuberculosis.

They are not dressed in white dust coats; neither are they carrying around stethoscopes – they use a simple innovation to solve a complex problem of people who are on TB drugs falling back on treatment.

*Keheala*, the mobile health company they work for, is improving healthcare access and treatment outcomes for TB patients through a mobile phone platform, which is free to download and a web platform. They remind them to take drugs at

the correct time through an SMS. The patients can also raise any issue they are facing and can be connected to a doctor in case of an emergency.

The platform is available to the patients at any time of the day and the information shared is confidential, meaning that patients can ask questions they would be embarrassed to ask a doctor.

"We work closely with the national TB programme to ensure people stick to the treatment regime. This enhances cost-effectiveness. The process starts from the county coordinator, sub-county coordinator, clinicians up to the patients level," says Edwin Nyakan, the project manager at *Keheala*.

*Keheala* means community in Hebrew and embodies their

bid to increase treatment adherence among TB patients.

Their work is to reduce the TB prevalence rate in Kenya. According to the 2017 National TB prevalence rate survey, there are more TB cases in Kenya than previously estimated. The survey put the prevalence rate at 558 per 100,000 people while the World Health Organisation estimates that the rate is 222 per 100,000 people.

During the pilot study, 1,200 patients were enrolled into the system. 605 of them interacted with *Keheala*. They received SMS reminders to take their medicine and could contact clinicians working with *Keheala* anytime they needed assistance. The rest went through the normal treatment procedure where they are given drugs

# Nearly any body part can get TB

*Contrary to popular belief, TB is not confined to lungs but can occur in any area apart from hair, nails and teeth*

by Sandra Wekesa  
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Mention Tuberculosis (TB) and images of a wasted person with a persistent bloody cough, chest pain, weight loss and night sweat spring to the minds of most people.

These are, in fact the typical symptoms of lung TB. However, people suffering from Extra Pulmonary Tuberculosis (EPTB), which can affect any part of the body apart from the hair, teeth and nails may not exhibit some of these symptoms.

Take Peter Kung'u, for example. When he developed a mysterious pain in one leg at 26, he assumed it was one of the common illnesses that would easily go away with over-the-counter medication.

### Symptoms

"I could feel pain occasionally and didn't know what to do because in as much as I was taking medicine the symptoms still persisted. With time I began to lose weight, I couldn't understand what was happening to me, I went to a nearby health centre and they still prescribed the same medication," he said.

With no improvement, Kung'u went to Kenyatta national Hospital (KNH) he was diagnosed with TB of the legs, a rare kind of the infection which didn't match up to the

## Report from National Tuberculosis, Leprosy & Lung disease Programme (NTLP)

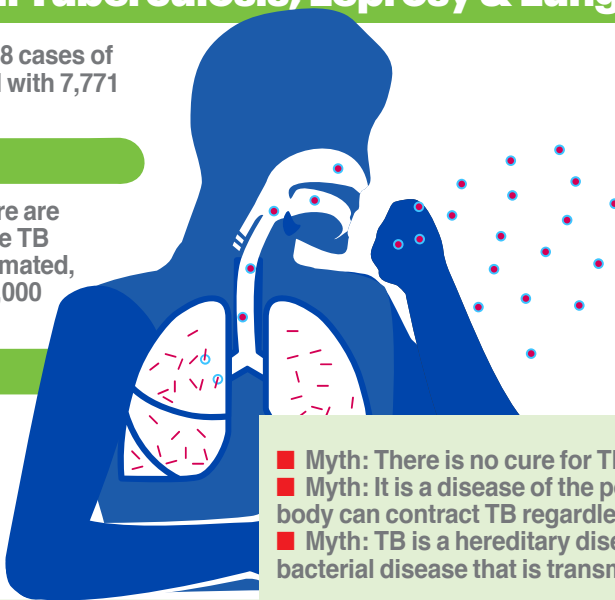
**85,188** In 2017 about 85,188 cases of TB were diagnosed with 7,771 of them affecting children.

### Prevalence rates

**558/100,000** There are more TB cases in Kenya than previously estimated, with a TB prevalence of 558 per 100,000 people.

### Age disparity

**25-34** TB was found to be higher in young men between the ages of 25 and 34 years, urban dwellers and women over the age of 65.



### TB and HIV

The majority 83 per cent of TB cases was HIV negative, suggesting that broad efforts at controlling TB in people with and without HIV are needed **83%**

### Recommendations

The use of the GeneXpert (an innovative technology for the diagnosis of TB) detected 78 per cent of the TB cases, among those screened, making it a more reliable and efficient test.

### Facts vs myths

- Myth: There is no cure for TB ■ Fact: It is entirely curable within 6- 12 months
- Myth: It is a disease of the poor and the rich can't be infected ■ Fact: Anybody can contract TB regardless of his or her socio economic status
- Myth: TB is a hereditary disease that runs in certain families ■ Fact: It is a bacterial disease that is transmitted from one person to the other.

### THE TWO TBs

A diagnosis of latent tuberculosis (LTB), also called latent tuberculosis infection (LTBI) means a patient is infected with *Mycobacterium tuberculosis*.

**Active tuberculosis can be contagious while latent tuberculosis is not, and it is therefore not possible to get TB from someone with latent tuberculosis.**

*“TB is preventable, treatable and curable as long as screening is done at the right time and the right medication prescribed”*

kind of symptoms he would expect.

National Tuberculosis, Leprosy and Lung Disease Programme (NTLP) assistant director of Public Health Samuel Misoï says vaccination and adherence to treatment is key to management of the infection.

"TB is preventable, treatable and curable as long as screening is done at the correct time and the right medication prescribed."

He says many people live with latent TB and show no symptoms because it neither makes them sick nor is it infectious.

"Only about 10 per cent of those with the living but inactive bacterium, which is called Latent TB, go on to develop the disease. This form of TB is not contagious," he says.

"You don't necessarily have to have a cough or weight loss

to identify cases of TB. It is especially more so in children. If they are less playful or are generally sickly, it's advisable to consider visiting the hospital," he adds.

Three years after the shocking diagnosis, Peter still carries on with his day to day

activities. He says he is glad he didn't let stigma take him down. "I couldn't walk, I had to use crutches to access most places. Many that heard I had contracted TB started avoiding me," he says.

Most of the time, EPTB is normally airborne and the

symptoms normally dwell on the organ that is harbouring the bacteria.

NTLP doctor, Eunice Omesa says, when it comes to EPTB visiting a health care facility is the best thing to do because they will deal with the problem at the primary level.

## combat tuberculosis

and visit the clinic regularly.

The pilot study had a treatment success rate of 96 per cent compared to 87 per cent of the standard of care group. Only 4.2 per cent of patients using *Keheala* did not successfully complete treatment compared to 12.6 per cent of patients in the standard-of-care control group. At scale in Kenya, the pilot study saved the government Sh9.3 million.

This impact translates to 1,553 lives saved, 329 fewer drug resistant cases and Sh2.4 billion in savings. The project will now be upscaled to eight counties including Nairobi, Kisumu, Kakamega, Machakos, Mombasa, Kiambu, Turkana and Wajir.

What is fascinating about the team made up of the founder, Jonathan Rathausser, an Ameri-

can based in Israel, Nyakan the team leader and Jill Ondigo, Fridah Njeri, Faith Muchiri, Lewis Muriuki, Alice Mwikamba and Teresa Adhiambo, all support sponsors, is how each one of them has had a personal interaction with the disease.

One is a TB survivor, one is a nurse who has worked with TB patients and others have taken care of a family member living with the disease or a chronic condition. They understand the struggles the patients go through and therefore give a human face to the interaction between technology and care.

"Some the patients were stigmatised by TB while others did not know the cause of the disease or how to manage it. I remember my interaction with a 19-year-old girl at a clinic. She

was there to pick her drugs but she did not know a lot of about the disease. She associated TB with HIV/Aids. When she got into the project she adhered to the treatment and could ask many questions. At the end of the treatment she did not feel stigmatised," says Adhiambo.

Rathausser brought the team together in 2016 after coming to face with the disease while teaching Lacrosse to youth in Mukuru slums how to play the game when he came face-to-face with the impact of TB in slums.

Based on the success of the project in Kenya, the United Nations Development Programme (UNDP) has hired the company to implement the intervention for TB patients in Zimbabwe.



**KenGen**  
Kenya Electricity  
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### PUBLIC NOTICE TO ALL KenGen SUPPLIERS

KenGen is in the process of implementing the Supplier Relationship Management (SRM) software which will Go-Live by end of April 2018. The objective of the SRM solution is to offer an online e-procurement platform through which KenGen will automate the entire procurement process. The system will also provide an online platform for interacting with suppliers.

In line with this objective, a number of our current business processes and documentation have been changed. To ensure that all our current and potential suppliers are aware of these changes, a briefing session has been scheduled to take place as follows:

**Venue: Stima Club, Ruaraka, Nairobi.**

**Time: 7.30 a.m. to 11.00 a.m.**

Date	Target Group
28 <sup>th</sup> March 2018	GROUP 1 Special Group – Youth, Women and Persons With Disabilities (PWD)
29 <sup>th</sup> March 2018	GROUP 2 All other suppliers

### SUPPLY CHAIN DIRECTOR