

Your Ref: TBA; Our Ref: C/KELIN/2012; Date: 10th February 2012

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2. Hon. Peter Anyang' Nyongó E.G.H., M.P.,
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3. Hon. Esther Murugi Mathenge E.G.H., M.P.,
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5. Hon. Prof Githu Muigai, M.P.,
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Dear Sirs,

RE: PROTECTION OF PUBLIC HEALTH & HUMAN RIGHTS IN RESPONSE TO A REPORTED CASE OF A PATIENT WITH EXTENSIVELY DRUG RESISTANT TUBERCULOSIS (XDR-TB)

A call to action by members of Civil Society Organisations (CSOs), TB Patients and Communities working on health and human rights issues: to urgently address the lack of investment in the treatment and care of XDR-TB patients in Kenya with specific regard to the case of Mrs X¹.

Following local and international media reports on the above case, various members of Civil Society Organisations working on health, HIV and human rights have individually and collectively investigated the case and would like to issue the following advisory note with respect to this case.

FACTS OF THE CASE

Mrs X a middle aged woman, who is HIV positive, was diagnosed with extensively drug resistant TB (XDR-TB), while receiving her treatment at the Kenyatta National Hospital (KNH) in October 2011 for multi-drug resistant TB (MDR-TB). The patient resides in Nairobi County, with two adults in a shared two bedroom house. There are also other adults that share a compound with the patient.

We have established the following pertinent facts, with particular focus on the issue of access to XDR-TB treatment for Mrs X:

- i. Although care and treatment is being provided to the patient by the Kenyatta National Hospital (KNH) and the hospital provides the prescription for the medication as per the prescribed regimen, the patient is required to purchase the three medicines herself each month. These include Viomycin (which is not registered locally by the Poisons and Pharmacy Board), Linezolid (Oxazolidinones) 600mg and Lclacid 500mg to supplement the treatment that she is taking.



- ii. Currently, Mrs X's family members spend Kshs 16,000 a week to purchase the Lclacid and Linezolid drugs from a private pharmacy on her behalf, as the patient is financially unable to purchase the medicines. They are equally responsible for her food and other social needs as well as for the family as a whole.
- iii. The family members have to regularly fundraise among themselves to raise the Kshs 16,000/= to purchase the medicines.
- iv. It has been established that Linezolid and Lclacid antibiotics are readily available at the KNH pharmacy.
- v. The estimated cost of treating patients with XDR- TB is approximately Ksh 3,000,000/= per year and is required for over a period of 24 to 36 months.
- vi. There is currently no policy in this country on how to manage patients with XDR-TB and no public statement has been made by either Ministry of Health on how the case is to be handled.
- vii. The patient has regularly travelled to hospital by public and private means to seek treatment. Now the KNH has provided N95 mask to the patient and the two adults who reside with the patient.
- viii. The patient still remains infectious and poses a risk of infecting others she comes into contact so ensuring she has access to sustainable treatment and infection control measures is crucial. It has also been established that there have been two other separate cases of patients with XDR-TB, who have regrettably all passed away as result of their condition.
- ix. The isolation ward ear-marked for MDR-TB and XDR-TB patients is yet to be completed, it has now been seven years since funding for it was provided in 2005 by the Global Fund
- x. The patient's immediate care givers have since been provided with counselling [through KNH] on how to care for XDR-TB patients.

GENERAL SITUATION OF TB

It is within the public domain that the two Ministries of Health are implementing initiatives towards achieving internationally agreed-upon TB control targets, including the TB relevant Millennium Development Goals (MDGs) with the immediate short-term goal being to sustain the gains already achieved with the 70/85 targets — that is, to detect 70 percent of infectious TB cases and to cure 85 percent of the detected cases, sustaining this effort over a prolonged period of time to achieve the MDGs. The TB MDG requires halting and beginning to reverse both incidence and mortality due to TB by 2015 and eradicating TB by 2050.

It is also public knowledge that Kenya has a large and rising TB disease burden and is ranked 12th among the 22 countries that collectively share about 80 percent of the world's TB cases. The prevalence rate per 100,000 adults in Kenya is 238, as of 2010 (Global Health Facts). Moreover, there is growing resistance to TB medications. In Kenya there are approximately 553 patients with MDRTB and out of them only 230 (43%) are receiving treatment for MDR-TB as at December 2011. Two patients have since lost their lives due to XDR-TB, in 2010 and 2011 respectively. The 57% of MDR cases have the potential risk of infecting 2,107 people in one year at the rate of 7 infections per year per one MDR untreated patient.

Furthermore in 2009/10 the main financing source for TB activities was donor funding, at 42 percent of the total health budget, followed by private (including households) and public sector resources at 30 percent and 28 percent, respectively.



WHY WE OBJECT

We would like to clearly state that we encourage and support the Ministry of Public Health & Sanitation and its officers in efforts to ensure that we reduce the incidence and mortality due to TB by 2015 and work towards eradicating TB by 2050 as outlined in the Millennium Development Goals (MDGs). We would like to, however, caution against the casual nature in which the case of the patient in question, and other patients with XDR-TB, have been handled.

In our view, this matter has not been dealt with the level of seriousness it deserves, particularly as it is a matter concerning the individual, community, national and global public health. The proper treatment and care of an XDR-TB patient, such as Mrs X, is of utmost importance as a public health issue. The question that must be posed is whether the government's lack of investment in the treatment and care of XDR-TB patients will result in further infections and greater costs in the long run, both in terms of a loss of life and depletion of other health resources. As stated earlier this would cost Kshs 3,000,000/= to treat one patient. A further question that must be posed is whether the government has made any effort, in absence of demonstrating capacity to deal with this case, to seek help from International organisations that offer TB and HIV related services.

We raise our concerns for the following reasons:

- i. The inability of government to guarantee a sustained supply of drugs to the patient, and [future?] XDR-TB patients, will continue to pose a risk to her rate of recovery and raise questions about the standard and quality of treatment offered to this patient. This may further have implications for drug-resistance if treatment is interrupted due to the patient not having sustainable access to the required medication.
- ii. The prescription of medicine to a patient that is not available locally (Viomycin) and the failure or refusal to provide Linezolid (Oxazolidines) 600mg and Lclacid (Chlarinhromycin)500mg, while they remain locally available, equally raises questions as to the seriousness that has been given towards the patient's treatment and also the meeting of the MDGs.
- iii. The absence of national guidelines on the management of XDR-TB patients and a lack of access to a sustainable supply of the required medication should further be seen against the backdrop of two recent deaths of patients with XDR-TB and 553 diagnosed cases of MDR-TB as at December 2011 with only 230 of them receiving treatment for MDR-TB.
- iv. The incomplete construction of an isolation ward for MDR-TB and XDR-TB patients, seven years down the line after receiving Global Fund money to construct the same clearly demonstrates the lack of coordination between government ministries and departments to address XDR-TB issues in a holistic fashion.
- v. The absence of legal clarity, authority and a government policy on the treatment, care and management of patients with XDR-TB creates a situation where a patient is managed in a mediocre manner, maintains a deterioration of health status/quality of life and would continue to pose a risk to the larger public of infecting them with XDR-TB, during her infectious stage, through no fault of her own by not being ensured continued access to the required treatment.
- vi. The lack of co-ordination on the part of government to involve civil society partners in response to dealing with this case again demonstrates the absence of utilising a participatory approach in dealing with TB issues.



- vii. Insufficient political commitment and guidance to adequately respond to the TB epidemic as demonstrated by the over reliance on development partners to support the TB programmes rather than focusing on strengthening domestic resources for TB. Currently the MSF programmes in Kenya are treating a minimum of 63 patients out of the 230 with drug resistant Tuberculosis.

These reasons point to the deplorable manner in which this matter has been handled and which will eventually undermine the very outcomes that the Ministries of Health hopes to achieve in their in eradicating TB by 2050.

Despite registering some progress, the National TB Programme faces some glaring challenges. The current example of the case of Mrs X best illustrates this. The case confirms that eradicating TB infections by 2050 will not be possible.

We must also point out the squandered opportunities, which if were prudently utilized, then our National TB Programme would register milestones. We particularly single out the Global Fund to fight AIDS TB and Malaria (GFATM) Round 5 (TB) grant which uniquely had a provision for the construction and equipping of isolation facilities for MDR-TB patients. Since 2005, the isolation wards have not been completed.

We wish to state that the success to the response to TB in all its forms in this country depends upon political leadership to properly direct and construct programmes that are based on evidence, particularly human rights, in light of the dispensation of our Constitution, and backed by sufficient financial resources. This requires the full involvement of civil society, private partners to be drawn, especially in the dealing of this case so as to aid the government to understand and address the concerns facing TB patients.

OUR RECOMMENDATIONS

In order to address the situation as effectively as possible, we wish to recommend that:

- i. As a matter of public health, the two ministries of health must give the attention that is deserved to ensure that XDR-TB patients receive sustainable treatment and access to the highest attainable standard of care, at the cost of the government and not the patient nor her family members.
- ii. We urge the government ministries to come up with a clear policy on how to detect and manage patients with XDR-TB. This should be done in a manner that respects the human rights of these patients as enshrined in Chapter IV of the Constitution of Kenya 2010.
- iii. We urge the government ministries to ensure the completion and full operation of the TB isolation ward for MDR-TB and XDR-TB patients before World TB Day on 24th March 2012, and ensure that the ward is able to administer the appropriate treatment to patients during their period of infectiousness
- iv. We urge the government ministries to ensure the prudent utilisation of resources that have been availed to the Country, to help improve the standard of care of persons who have infectious diseases.



- v. We urge the government to utilise the same speed and resources that were used in arresting Mr. Daniel Kipnegtich and Mr. Patrick Kipnegtich Kirui in Kapsabet two years ago for defaulting on their TB medication for reasons of absence of support systems, poor information from service providers and clear policies on isolation of patients, and provide the requisite health services for this patient as is required by Article 43(1) a of our Kenyan Constitution.

Signed



Allan Maleche

Coordinator, Kenya Legal & Ethical Issues Network on HIV & AIDS (KELIN)

SIGNED BY KENYA LEGAL & ETHICAL ISSUES NETWORK ON HIV & AIDS (KELIN) ON BEHALF OF THE FOLLOWING ORGANISATIONS

- Action Aid International Kenya (AAIK)
- Aids Law Project Kenya (ALP-K)
- Alliance for Care and Prevention of Tuberculosis in Kenya (ACT KENYA)
- Health Rights Advocacy Forum (HERAF)
- Kenya Aids NGOs Consortium (KANCO)
- Kenya Consortium to fight AIDS TB and Malaria (Kecofatuma)
- Kenya Medical Care Development International - Kenya
- Kenya Network of HIV Positive Teachers (KENEPOTE)



- Kenya Network of Women Living with AIDS (KENWA)
- Kenya Treatment Access Movement (KETAM)
- Lean On Me Young PLHIV Group
- National Empowerment Network of People Living With HIV and AIDS Kenya (NEPHAK)
- Kenya Hospices and Palliative Care Association (KEHPCA)
- Network of Men Living With HIV & AIDS in Kenya (NETMA)
- TB Action Group
- VSO Jitolee
- Women Fighting AIDS in Kenya
- Wote Youth Development Project



CC:

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ENDNOTES

Mrs X's name has been protected for reasons of privacy. Please contact Allan Maleche, Coordinator of KELIN for further information on amaleche@kelinkenya.org .

