Personal stories of women and transgender with TB/MDR-TB/TB-HIV

PHOTO CAPTION: Mother of a girl child with MDR-TB currently on treatment (left) and cured MDR-TB woman (right) speaking at a session in St Stephen’s Hospital, Delhi
Citizen News Service (CNS) specializes in health reporting from a rights’ based perspective and also supports a policy advocacy and communications campaign for health and gender justice.

This document presents CNS interviews with young girls, women and transgender who have dealt with tuberculosis (TB), multidrug-resistant TB (MDR-TB), and/or TB-HIV co-infection; and female care providers in families with TB. The photographs and interviews were done with consent and names have been changed (where requested) to respect confidentiality. These interviews were done by Shobha Shukla (CNS Managing Editor) and Masimba Biriwasha (Zimbabwe CNS Correspondent) in 2012-2013.

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*I like the night. Without the dark, we’d never see the stars...*

*Stephenie Meyer, Twilight*

Personal stories of women and transgender with TB/ MDR-TB/ TB-HIV
Chandrika’s Fight Against The Deadly Virus-Bacteria Duo

Chandrika Gaud is a 28 years old transgender of Mumbai who is living with HIV as well as with drug resistant TB (DR TB). She is currently on second line antiretroviral drugs and DR-TB medication. Her HIV status was detected in 2006 and DR-TB status was confirmed in 2010 when she was referred to MSF. Before coming to MSF she had already taken TB treatment twice. She recently spoke to MSF about her struggles to cope with the double burden of her illness.

By her own admission, Chandrika earns her living by begging in the basti (area) around the place of her residence. (In India, it is still customary for the transgender populations to sing and dance in households, where a wedding has taken place or a child has been born recently, for gifts and money in return. This, along with begging, is their livelihood).

She lives with a few other community members, comprising her grandmother and some of her disciples (juniors perhaps). They live close to each other in a group, but she insists that, “I live alone in my house. My house is separate. My kitchen and my bedroom are all separate. I do not live with others.”

In 2004 she had very severe cough, accompanied by chest pain. “I used to cough a lot with a lot of phlegm. I thought it was because of eating jujube berries (‘ber’ in Hindi language). My guru, my disciples and everyone else thought that the fruit caused chills and was responsible for my cough. I was very fond of this fruit but then I stopped eating it. But my cough did not improve. So I went to a doctor who told me that I had TB. He said that the cough was not because of the berries, but because of my TB.”

Chandrika was nonplussed. She did not have the faintest idea about TB. “I did not understand what he meant by TB? What was it? So I just stood there quietly.” Nonetheless she completed a 9 months free TB treatment from Sewree Hospital in 2004. (This is as per her records, although in her interview she said that it was a 6 months course). Yet she felt that her body did not respond to the treatment. “I would just feel very sleepy all the time. No matter how many medicines I ate, it made no difference to my condition. I would start panting while climbing stairs. I would get breathless.”

Then, in 2006 she started feeling unwell again, with giddiness and loss of appetite. At the insistence of her grandmother and her guru (teacher) she went to see a doctor.
who diagnosed her with HIV/AIDS. She was put on Anti Retroviral Therapy (ART) at KEM ART Centre in 2007.

But after sometime her cough returned and she started feeling very weak. She lost weight and did not feel like eating and felt like vomiting. So she went again to the hospital where a blood test was done and in 2009 she was again put on ATT for 6 months at the same hospital at Sewree. She took all the precautions advised by the doctor. They told her to eat her pills and to avoid cold things. So she stopped drinking cold water and/or any fruit or food kept in the fridge. She thought that this would control her disease, but wondered why, despite taking all precautions, her cough would not go.

Chandrika could not understand why she had to take the second course even after eating ‘such good medicines’ which did not prove to be effective. When she asked the doctor, he said that he was not sure if she had earlier eaten the medicines properly. He assured her that her cough would improve after 6-7 months. But this was not to be. Her condition did not improve and she felt very unwell. Then she went to KEM Hospital, where she had earlier been on ART. But they would only test and treat for HIV, and not for TB. From there she was referred to MSF in 2010. MSF suspected her of having DR-TB, did culture test which was positive. So she was started on DR-TB treatment.

Thus after being driven from pillar to post she could finally start on a two year long proper course of treatment for DR-TB only in 2010. In the beginning, when she started her medication of DR TB, she suffered from severe side effects. In her words, “I always felt like vomiting, there was no appetite. It was a real torture to eat 9 pills. I thought it is better to die rather than eat so many medicines. I had also to take injections every day.”

But it was the love and care of her grandmother which kept her going. She remembers that, “My grandmother would always persuade me to eat my medicines. She would say that to get well I must eat them. So after being forced to eat them, I would walk for 1-3 hours and the sleep for one hour. I would feel better after this one hour sleep.”

Chandrika has already completed the intensive phase of her treatment and is currently in its continuing phase. She is now determined to take the complete course of medicines and not leave in between. She is scared that, “If I leave them, I will die. What would be the use of taking medicines for so many years, if I leave now? If I do not complete the course, it (TB) would restart again. I would definitely continue and not leave it in between.”

She recalls the discrimination she faced in her community because of her disease. Her own people would look down upon her and shun her like an untouchable. They would all stay away from her. If she asked somebody to oil her hair, she was shooed away.
She could not go and visit her village and other places. She stayed indoors and would not sit with others. She could not go out for work also.

But since she has come to MSF, her condition has improved. She feels that the pills which she gets here are so very different. There is no cough now and her appetite has returned. Above all, her community has taken her back in their fold. She is no longer despised by them. They have started talking to her nicely once again. They compliment her, ‘Now you look so beautiful, you are back to your normal self. Touch wood.’ She is very happy that now her acquaintances love her like before and she too has started taking an interest in her life. The earlier weak and despondent Chandrika is no more. There is hope and happiness in her life once again, and for this she is very grateful to all the staff of MSF.

Her message to all is that one should not neglect TB. According to her, “Some people neglect TB treatment, and don’t care for their lives. But I think it is better to live well by eating the medicines, and completing the course of treatment rather than die unnecessarily. If people get the medicines which they need it would be very good. Then they will get cured. So, all those who are in need of it must get the treatment for TB.”

A Caring Treatment Conquers All Odds: Story of Shanti

Shanti is a 38 year old semi literate woman of slender means living in Mumbai. She has been living with HIV since the last 5 years and had developed multidrug-resistant tuberculosis (MDR-TB). Her story is the story of the common person on the street for whom each day’s survival is an ordeal, even when there is no illness. Taking treatment for the double burden of HIV-TB co-infection makes it like the last straw on the camel’s back. Shanti recently spoke about her trials and tribulations to Medicins Sans Frontieres (MSF) — in whose care she was brought for treatment of MDR-TB around 4 months ago.

Hers is a beautiful life gone ugly. Her first husband died of AIDS in 1991, and her only daughter passed away a few years ago. She reminisces about her past, and rues about her present: “I was born and bred in Mumbai. My childhood days were really good. I loved playing on the beach and clicking photographs. Later, after I got married, I used to come here (Chaupatty Beach) often with my daughter and my
husband and enjoyed being in the water. But now I do not go out anywhere to travel and visit places. I am so tired and sick all the time. I am not even able to celebrate any of the festivals. My life has become hell as it now revolves around medicines only. I wish those good old days would return!”

Her tale of woes began in 2006 when she became very sick with diarrhea, recurring bouts of fever and vomiting. She took treatment from private doctors. At that time she was working along with her husband. But all the money would be spent on her illness. She remembers that, “I would remain okay for a month, and then the problems would start again. I even got tested for HIV in the private sector. I paid Rs 400 (USD 8-10) for the test but was told that it was negative. But later my HIV status was confirmed and in 2007 I was put on antiretroviral therapy (ART) in JJ Hospital.”

However, getting diagnosed, and treated for her sickness of drug-resistant TB, proved to be a far more formidable task. Three times the sputum test she gave at the municipal hospital in Marine Lines came back with a negative result for TB. Yet, even without proper confirmation of her illness, she was put on a TB treatment course for six months. She had to take 24 injections as well as pills on alternate days. But her health did not improve and two months after completing the treatment she went back to the same hospital and on the basis of the results of an X-Ray (which she got privately done, outside the hospital) she was given another eight month treatment course.

But she did not get any better even after this, and continued to suffer from weakness, loss of appetite and a very bad cough. But she was refused medication by a doctor who told her that he could not put her on a third course of antibiotics, else her kidneys would get damaged. “I was already on ART then at JJ Hospital. But the treatment was not working effectively. My health and appetite was not improving. I told the doctor there that I had taken two courses of anti-TB medicines. Then I was made to fill a form and sent to the hospital in GT. There again I completed a 6 months course of tablets plus injections for TB.”

Finally in 2007 doctors at JJ Hospital diagnosed her of having drug resistant TB (DR-TB), but told her that it would not be possible for her to afford the costly treatment. A social worker at the hospital told a distraught Shanti that, “There is no cure for it. Its treatment is very expensive. From where will you get lakhs of rupees? So you should eat proper diet and continue with ART lifelong. If you discontinue ART you will die.”

Shanti was very disconsolate. She had already undergone the full course of TB treatment thrice - two 6 months regimens and one 8 months regimen over a period of time, but, instead of improving, each time her situation had worsened. Luckily, a contact put her in touch with someone who arranged an appointment for her with MSF in November 2011, where finally she was put on the correct treatment for her illness. She is now she is in her fourth month of treatment for drug-resistant TB with MSF. But
as she is also infected with HIV (and on ART since 2007), the number of pills she has to take each day is very high. She says, “My pill burden is very high. I have to eat too many medicines for TB alone—6 tablets in the morning and 8 tablets at night. In addition I have to take antiretroviral medicines also. Sometimes I vomit out a few tablets—so I have to take some medicines to prevent vomiting. I have to get injections too. If pill burden is reduced it would be a great relief. It seems that medicines have become my food now. There are more medicines in my stomach than food. The doctor says that when my weight will increase, the amount of medicines will decrease. But as of now my weight is not increasing. I have been advised to take fruits and milk, but my stomach is not able to digest milk and curd. Life at the moment is bad.”

The side effects of all these medications are very difficult to cope with. She rues that, “I am not able to eat properly. I vomit all the time and feel drowsy the whole day long—as if I am drugged. My mind does not seem to work, I feel very distressed. There is too much of palpitation all the time. It seems as if I would die. I feel giddy after taking my medicine, and also feel unbearably hot.”

Her living conditions are also inadequate. Over the years, she has spent most of her earnings on tests and medicines. After the death of her first husband she has been living with one of his friends, whose love and care are her only hope. Her alcoholic brother and old mother (living with diabetes) also live with her in very poor conditions. Shanti complains that, “I do not even have a proper place to live in. My house is very small and in a very poor condition. I have no electricity connection. There is no fan, so it becomes very hot. I feel very hot when I eat the medicines. There is too much of sun, and there is problem of bathing also. I need a place where I could sleep under a fan and rest after eating my pills.”

Her eyes brim with joy and her face shines with the love of her caring partner. He has been her only anchor in the stormy path of her life. In her words, “My husband always gives me hope. He is my source of courage I am alive because of him only. I got married to him after the death of my first husband. I have so many ailments, but instead of leaving me to my fate, he takes very good care of me. He even washes my clothes and helps me to take a bath. If it were not for him, I would have left the treatment long ago. It is his courage and faith that keeps me going. I had lost all hopes of living. I just wanted to die. I did not want to take any medicines or injections. But I swallow the medicines for the sake of the love of my husband, who says—‘if you die I too will leave this world’.”

Shanti has been lucky to have a very supportive partner, and luckier to have come under the care of MSF, (through the efforts of one Sharmila Madam and Roma Madam), where she is now receiving free treatment for DR-TB. This is like a silver lining in her otherwise bleak existence. But thousands others are not that fortunate. They often fall prey to misdiagnosis by unqualified doctors in the early stages of the disease. Even when the treatment begins, it may not be completed due to a host of reasons—expensive treatment, pill burden, adherence issues, toxic side effects of
medicines, and above all, a total lack of knowledge and awareness about the disease. So they simply languish in miserable situations, just waiting for death to end their tribulations. It would be a great day indeed when a loving and caring treatment is accessible to all those in need of it, irrespective of their social and economic status.

A woman's courageous journey through TB treatment

In 2005, Tariro Jack, 27, fell ill with Tuberculosis (TB) during her first year at college. She said that she struggled to cope not only with her own health but also managing people’s perceptions. TB is an infectious disease that spreads through the air. The disease mostly affects young adults in their most productive years and 95% of TB deaths are in the developing world. Estimated TB incidence rates are highest in sub-Saharan Africa with over 350 cases per 100,000 population. Among African nations, Zimbabwe is one of those most heavily affected by TB. The deadly combination of TB and HIV epidemics is igniting a silent and uncontrollable epidemic of drug resistant TB that will negate previous national health gains.

"I had TB at 21 in my first year at college and I know people thought that I was dying; I struggled a lot," Jack said, adding that when she was put on the World Health Organisation (WHO) -recommended Directly Observed Treatment Shortcourse (DOTS), matters only got worse as her health further deteriorated.

"My skin was very smooth. When I started taking pills, I developed a rash and my legs became sore to the extent that I couldn't walk," she said.

"Every time that I took the pills I would feel more sick that before and after, I used to throw up a lot. I used to go to the toilet frequently because the pills upset my whole system."

To complicate matters, her doctor at the time told her that she was not responding well to the medication and recommended that she go and see a specialist. Other health officials did not help the situation by predicting Jack's demise.

"I remember there is one time I was admitted to hospital and the sister-in-charge told the nurses not to waste their time on me because I was good as dead. That gave me strength to fight for my life," she said.

Due to the close association between TB and HIV, Jack said that she had to contend with another struggle, that of being suspected to be HIV-positive. TB is a leading cause of illness and death for people living with HIV - about one in five of the world’s 1.8 million AIDS-related deaths in 2009 was associated with TB. The majority of
people living with HIV and TB are in sub-Saharan Africa. In spite of this close association, it is not automatic that when one has TB, they’re also HIV positive. Stigma around this association is portent though and can lead affected to shun seeking medical attention.

“When I had TB, everyone seemed to think I was HIV positive. I went for countless HIV tests and everytime they came out negative. This was to prove a point but I later realised I didn’t live for people but for my self,” Jack said.

"I finally got better as I followed the treatment course until I was fine and I thank God because people who did not know me at the time cannot in any way tell that I once had TB.”

She said that the negative attitude that she received from some of the health personnel is still like a fresh scar in her memory.

"To people with TB, whether you’re HIV-negative or living with HIV, what you’ve to know is that TB is curable. You should just believe in your self and have a thick skin because people will always talk but I thank God because He gave me strength and now I can tell everyone of my experience. TB does not kill. Don’t let anyone lie to you,” she said.

(As told to CNS Zimbabwe Correspondent Masimba Biriwasha)

**Persistent low grade-fever & cough...**

40 years old Rukmini lives close to the Civil Hospital of BJ Medical College in Ahmedabad. She used to sell fruits to supplement her daily wage earner husband’s meager income till tuberculosis struck her in 2010. She has a 17 year old daughter and an elder son who is married. Rukmini is illiterate but she managed to educate her children up to elementary level.

“Three years ago, in 2010, I started having persistent low grade fever and cough. There was never enough money in the house, so I took treatment intermittently in the private sector, as and when I had money. But one and a half years ago my condition worsened. I was breathless all the time and could not even walk properly. So I eventually came to this government hospital (BJ Medical College) where I was admitted for 3 months for TB treatment but was eventually diagnosed with MDR-TB.
My family is very supportive despite the infectious nature of the disease. My husband always accompanies me to the hospital.”

Unfortunately, Rukmini’s daughter contracted MDR-TB through her mother and has been on MDR-TB treatment in the same hospital since the last 6 months. The attending doctor told me that, “Direct MDR-TB transmission through contact is common. So if a family member of such a person has MDR-TB we test for MDR-TB in the beginning itself and if diagnosed put him/her directly on Cat-4 treatment.”

When I met Rukmini in February 2013 she was admitted in the MDR-TB Ward of Civil Hospital of BJ Medical College, Ahmedabad for breathing problems. TB had perhaps caused irreversible damage to her lungs. Although she has already tested negative she is in and out of the hospital because of breathlessness. Still she feels that there has been a vast improvement in her condition as compared to when she began her treatment.

“When I came to this hospital one year ago, I was bedridden. I could not walk without help and could not even drink water. Now I have become mobile once again and the credit for this goes to the doctors and nurses of this hospital, especially Dr Kusum Shah under whom I was admitted initially for 3 months. They have given me a new lease of life. They have really counseled me well and I follow all their instructions regarding infection control methods at home—I spit in a spittoon given by the hospital, I bury my spit in mud, I keep my house very clean. I hope I will soon be able to go back to my work of selling fruits and not remain a financial burden on my loving husband.”

The attending doctor, Dr Purvi, was all praises for Rukmini as she has been a very good patient and has diligently followed all the instructions given to her by the doctors.

Rukmini’s message for other people with TB: We should not take treatment in the private sector. The MDR-TB drugs which are given free at the government centres are very good and all people with MDR-TB must take them. Nobody must stop the treatment in between.
Adhering to treatment, but lost hearing power irreparably...

I met 19 year old Reena at the MDR-TB drug dispensing counter of RB TB hospital, New Delhi, where she had come to take her daily dose of MDR-TB medication. Her hearing power had been impaired irreversibly due to side effect of medicines. So I communicated with her through pen and paper and she replied orally.

Reena began her TB treatment from this hospital, six years ago in 2007. She had been suffering from shortness of breath along with chest pain and was told that there is water in her lungs. Six months of medication cured her of her problem and she got well. But after three years she was sent to look after her married sister who was suffering from TB (the sister died eventually). She contracted the disease again from her. Reena was in class 9 at that time but was forced to leave her studies because of her illness. Her teacher asked her not to come to school. She had reached the continuation phase of her treatment and was on the path of recovery.

Her MDR-TB treatment started in this hospital in July 2011 and she was put on continuation phase in March 2012. Dr Anuj Bhatnagar informed that she has been testing negative after 3 months of treatment, which is an ideal response. She has taken the treatment well and has high chances of a complete cure, more so because she is young.

Reena said, “I am now feeling much better. Earlier I was not able to walk properly and I lost a lot of hair—I almost turned bald. Now I just have hearing problem otherwise I am okay. My two married sisters died of TB, but I want to live and lead a normal TB free life. I love to watch old movies and eat meat, fish and eggs. I would go back to my studies once I am okay.”
Aspiring for size zero, acquires TB...

17 years old Rehana is a petit and very soft spoken 17 years old girl studying in Class 11. She lives with her parents (her father has a shop selling readymade garments), three brothers and a sister in Baratalla in Kolkata. Like other girls of her age she was very calorie conscious; went on a strict diet control to remain extra slim at the cost of her general body immunity, which went down too along with her weight.

She fell ill around 20th August 2012 with severe cough. She was shown to a private doctor and her treatment started on 29th August. She ate the medicines for whatever period of time they were prescribed. (Neither she nor her mother were able to recall the exact duration of the treatment). She had to take over 80 injections as well. To make matters worse, her liver was also affected and she got an attack of jaundice. She continued with the same doctor but her condition did not improve. She would feel nauseas and vomit all the time. Eventually the doctor said that as the medicines were not improving her condition, she should be taken to a government hospital. Her parents, in the absence of any proper knowledge about TB, took her to a government facility in Baratalla where her sputum tested negative. From there they were directed to Aamtala hospital where the sputum test result was positive for MDR-TB. She was then sent to K S Roy Hospital in Jadavpur.

When I met her in the MDR-TB ward of the hospital on January 24, 2013 I found her a very pale and frail looking girl. She had already
spent two weeks in the hospital and her medication had begun just 5 days ago. The nurse told us that as her condition had deteriorated after admission, she was being allowed to stay in the ward till she felt better, although normally people with MDR-TB are hospitalized for not more than 7 days for treatment initiation. Rehana said that she was already feeling a lot better than before. Some cough was still there but her appetite had returned. Her mother, who was attending on her, complained that, “Rehana has always been a poor eater and never cared for her health. She started dieting when she had put on some weight. So she started eating very little. Maybe this is one of the reasons for her to get the disease as her body immunity must have become low. She never listened to me. My house is in a mess. I have another 12 year old daughter who is looking after the house and has stopped going to school as there is no one else to do the family chores. I am staying here in the hospital day and night. No one else in our family has ever had TB.”

I wished Rehana good luck and told her that she should go back to studies once she is cured, and look after herself well and eat well. That brought a smile to her pale face and she promised to do so.

Instead of heralding social change, she turned positive for TB...

21 years old Neelam Das is a graduate and aspires to work in the police or the railway department, or else become a teacher as teachers can bring a positive change in the lives of students. Her father works in the blood bank of SSKM Hospital, more commonly known as Presidency General Hospital or PG Hospital Kolkata and the family lives in the PG Quarters inside the hospital campus.

Neelam’s problems began in January 2012 when she had a slight cough accompanied with a persistent high fever. The doctor at PG Hospital said that there was accumulation of cough in the chest and medicines would make it okay. She completed a 9 month course of ATT despite undergoing severe nausea and vomiting during the course of treatment. But at the end of the treatment there was no relief. So her sputum was sent for culture on 8th October 2012 and the culture report came after three months on 8th January, 2013, confirming diagnosis of MDR-TB. She was admitted in KS Roy Hospital,
Kolkata on 10th January for pre-treatment evaluation and initiation of MDR-TB treatment. Her medication started on 19th January and she was to be discharged on 28th—4 days after I met her on 24th January.

No one else in Neelam’s family, including her two younger brothers, has ever suffered from TB. But all of them, including her college friends have been very cooperative and stood by her side during her illness. Neelam’s mother, however, who was attending on her, complained that, “Neelam is a poor eater and that could be the reason for low immunity level of body. She would go on an empty stomach to college. Now since the day she has started eating medicines she does not eat as she is scared that she may vomit out the medicines. The sisters have asked her to eat well and drink 6 litres of water every day.”

Neelam said that she felt nauseous after taking medicines in the morning but felt better by evening. However she promised that once she goes home she would follow all the instructions given by the nurses regarding diet and infection control. She was very appreciative of the nursing staff of the hospital and said that they were changing the lives of people with TB for better.

Neelam told me that she loves to read and study. Even earlier, while on treatment, she managed to appear for her exams despite high fever. She is determined to pursue her post-graduation once she is cured.

(“The nurse in the ward said that for some unknown reasons the incidence of TB is very high in the PG Quarters area which she called a den of tuberculosis.”)

Personal stories of women and transgender with TB/ MDR-TB/ TB-HIV
Surviving bravely despite TB, diabetes, other health concerns...

Krishna Dalal is a housewife and has studied till Class 10. Her husband works as a peon in Calcutta University. She has a 14 years old son and a 10 years old daughter. Nobody else in the family has TB—they have all been tested for TB and are free from the disease.

“I was diagnosed for the first time in 2007 with early symptoms of fever and cough. I then took treatment from a private doctor for one year and got cured and then my medication stopped. I have also had diabetes since 2006. I was okay for two years, but in 2010 my fever and cough reappeared. This time I went to a DOTS clinic and then I took medicines from there for 8 months and was okay. But my culture report was again and again coming incorrect due to some problem or the other or my bad luck. Finally my medication for MDR-TB started in April 2012 and it has since been 9 months that I am taking those medicines. There were several problems related to my TB diagnosis, either there was some problem in quality of sputum or sending of sputum, or in the diagnosis. I really do not know. But now (February, 2013) my report has turned negative for MDR-TB. I have also started feeling much better. Earlier I was totally unable to do my domestic chores but now I have started with some small work at home. I still have minor problems of side effects of medicines but they are less than before.”

“I have been asked by the doctor at Calcutta Rescue Centre to wear a mask whenever I open my mouth to speak or else cover my mouth with a handkerchief when I go out, as a preventive measure for infection control. I have been coming every day to Calcutta Rescue Centre to take my medicines for the past 9 months and the place is not so far from my home. I have taken injections as well for 6 months. When my report came negative, injections and pyrazinamide were stopped but other medication is continuing. I have been told that the
treatment will last for 2 years. This centre is very good and the staff here is very understanding and caring.”

Krishna’s message to other people with TB: Cure for this disease is possible. However one needs to have patience, and although one might face many problems in the beginning by way of side effects of medicines, but in the end all will be fine. Slowly the person recovers from the disease if he or she takes proper and continuous medication as prescribed. So one must have patience and take medicines regularly.

(Babita, the nurse in charge at Calcutta Rescue Centre, Kolkata told: --Krishna is a person admitted in Ward 3. Hers is a sad story as twice she took TB treatment in private and twice Cat 2 treatment in the government set up before her MDR-TB was diagnosed. She is very faithful towards taking medicine. Her family and she are educated and the family is very supportive. In 2006 she took Cat 1 medicine from a private doctor for 8 months. When she came to our centre I saw her prescription and found that she was neither given proper medicines nor the proper doses. Her body weight was nearly 80 kg but rifampicin and INH dose given was not appropriate to this weight. I suspected that she must have become drug resistant. She was very upset that time. But then she took Cat 2 medicines from our centre and became negative. I was very happy and thought that my earlier presumption about MDR-TB was wrong. But after one year she returned with the same problem. So I requested the government doctor to send her sputum for culture. But at that time there were problems of sputum cups not being available in government set up, so there was more delay. Then I requested my DTO Dr Singh and with his help her sputum was sent for culture and she tested positive for MDR-TB. Only then could she be put on proper treatment and now she has tested negative and is in the continuation phase.)

Misdiagnosed as typhoid but had TB...

This is the story of Nusrat--I am 19 years of age and I have in my family my mother, father, 4 brothers and one younger sister. My father is a labourer.

This disease happened to me in 2009 when I was in class 7. I was then diagnosed with typhoid. But despite taking treatment for it the high fever continued. So I went for a complete checkup and was diagnosed with TB. I took treatment for 9 months from a private doctor. But there was no improvement in my condition—rather it worsened. I vomited a lot, had high fever and lost weight. One day I spitted out blood from mouth which really scared me and I stopped eating the medicines. My mother took me to our village in Amethi near Lucknow during school vacations. But there my condition
Personal stories of women and transgender with TB/ MDR-TB/ TB-HIV

became worse. I was so weak that I could not get up from bed. I returned to Kolkata and showed myself at Calcutta Rescue Centre. Thus I was put on Cat-2 treatment for TB in 2010. I had to take injections too. But when the treatment was completed I again fell ill. So I was on Cat-2 regimen again in 2011. Still I did not improve and my reports came out positive. Then my sputum was finally sent for culture and the report came after 4 months and I was diagnosed with MDR-TB. So since 16th February 2012 I have been taking medicines for MDR-TB from Calcutta Rescue Centre.

Now I am feeling much better and I walk to this centre alone every day after attending school to take my medicines. I had to discontinue my studies because of my illness and lost two years. But now on the insistence of Babita didi I have recently taken admission in class 9. I am really happy to be back to my friends and teachers.

The doctor has asked me to take some preventive measures at home which I follow religiously— I have my separate bed at home; I have separate utensils to eat my food and a separate water bottle. I do not eat with my siblings. Even in school I keep a handkerchief on my mouth while talking or sneezing.

Nusrat’s message to other persons with TB: I want to tell all other people that they must take proper medicines and on time and should never miss even a single dose. They should adhere to their treatment and complete it and not leave it in between.

(Babita, the nurse in charge at Calcutta Rescue Centre, Kolkata told—Nusrat took medicines from some private doctor for about a year in 2009 and came to Calcutta Rescue in July 2010 for Cat2 treatment. As her body weight was very low (about 22kg) she was given pediatric doses and also given streptomycin injections. Thereafter her reports came negative and she was cured by March 2011. But just one month later, on 27th April 2011, she came back with the same problems (low grade fever and cough). Her sputum tested positive again. Then she was put on Cat2 for relapse. But by now she had already taken Cat 2 treatment twice—once in private and then in government. Yet she was not responding. So finally her sputum was sent to the government hospital for culture and after 4 months the report confirmed MDR-TB and she was then put on Cat4 treatment. As per our rules she was admitted it K S Roy Hospital for fifteen days for observation and took medicines from there. Thereafter she has been on MDR-TB treatment for over a year now (it was February 2013). The results of the culture and smear are now coming negative and she is slowly getting better. She is now in the continuation phase and comes here alone every day to take her medicines. Her mother used to come with her when she
was getting injections, but now she comes alone. Sometime ago she developed some psychological problems-- sitting all day at home with nobody talking to her. So I advised her family to send her to school again as she was now infection free. She thought that she had become overage for her class. But then I counseled her and her family and told her that age is never a bar for studies. So she rejoined her school in January, 2013 and is now very happy going to school and talking to her friends. Her school does not know about her TB status. From the school she comes here to take her medicines. Earlier she would cry all the time but now she is back to being a normal and happy girl).

When I spoke to Nusrat in February 2013, she sounded very optimistic and full of hope. Going back to school had perhaps worked wonders for her mental health. She was happy to be with her friends once again and no longer treated as an outcast. There was no trace of dejection and depression in her talks. In fact she promised to meet me on her next visit to her grandparents’ house in Amethi.

**After a whirlwind search for cure, found relief at PMDT site in Delhi**

In the MDR-TB OPD of Lok Nayak TB Hospital I came across the harried father of a 19 years old girl who had reached Delhi that very morning of February, 2013 and then had immediately come to the hospital. His daughter’s case had been referred from SGPGI Lucknow to this hospital.

His heart rending tale of woes was a living testimony of a callous and irresponsible private sector and a careless government sector. He was carrying a fat load of her past prescriptions gathered as the hapless father went from one doctor to another; from one treatment to another; while her TB got worse by the day.

The duo belonged to MP
where the girl first took ill in September 2010. She had constant fever and cough. Her sputum was tested and X-Ray was also taken. She took treatment under a private doctor for 8 months. She was okay for 4 months and then the problems recurred. This time the father took her to a government hospital in Chhatarpur where she was again put on a 9 months regimen. But the medicines had to be bought from the private market as the government doctor was treating her as a private patient (the father said that this was quite the norm at his native place. Here she was given kanamycin 750 mg injections for 3 months on alternate days, but not streptomycin. Yet there was no relief. For two years she was treated in MP but did not improve even one bit. The person with TB as well her parents were all fed up with the long drawn out treatment without any visible relief. Then on a relative’s advice she was shown in SGPGI Lucknow in June 2012. There she was given 60 streptomycin injections. Kanamycin was also started again. As per her SGPGI prescriptions she had been on 2nd line drugs since 1st November 2012.

For the last three months she had had no fever or cough and for the first time after 2010 she was feeling better. But probably the right treatment came to her a bit too late-- one of her lungs had been damaged almost completely and she was also suffering from a total loss of appetite. So she had been referred to this hospital.

(The attending doctor in the OPD went through all her past prescriptions very rigorously and concluded that she although she had been given kanamycin earlier by the doctor in MP, but other second line drugs were not given. So she developed resistance. The SGPGI doctors followed the protocol. Their tests revealed MDR-TB and they treated her accordingly. But they were not able to get the desired response. So now they doubted that she is resistant to second line drugs also—which means that it could be a case of XDR-TB. The doctor also said that as per the rules, if XDR-TB is diagnosed, this hospital would not be able to provide free drugs to this outstation patient, although they would give other support. Drugs from the private market would cost around INR 5 lakhs, for the whole course of treatment. However, he said that they would try to register her under some project or the other which go on in RB TB Hospital and LRS Hospital, and if she is lucky she would get free treatment under them. But there was no guarantee of this).

Deserted by husband’s family, in her father’s care: she needs an oxygen cylinder to breathe...

I met 18 years old Rinki in February 2013 in the Model MDR-TB Ward 8 of LRS Institute, Delhi. (There are 24 such state of the art wards in this hospital which are one of their
kind in India and are equipped with the most advanced infection control gadgets). She was breathing through an oxygen cylinder fitted in her ward. Rinki had completed 18 months of her MDR-TB treatment at LRS Institute in February 2013. She had tested negative and was in the continuation phase of medication. However TB had taken its toll by way of damaging her lungs, making her dependent on an oxygen cylinder to breathe. When she does not use the oxygen cylinder she suffers from intense body pain and feels very uncomfortable as she gasps for breath. The oxygen cylinder seems to have become her lifeline now as TB has ravaged her lungs.

Rinki comes from a very poor family and could study till class 6 only. She was married at a very young age, but was thrown out of her in-laws house when she contracted TB. A native of Bihar, Rinki lives with her parents and brother in a slum of Delhi. Her brother is a roadside vendor and the sole bread winner. Her father, who stays with her in the hospital from 4 pm till 10am, is a patient of hypertension. He used to ply a rickshaw but now his health does not permit him to do that. Rinki’s mother is also sick with many gastric ailments.

Rinki was put on TB treatment in 2009 when she was 14 years old. She completed 6 months therapy at LRS Institute and then tested negative. She remained okay for 6 months. Meanwhile she was married off by her parents (despite being so young and recuperating from a debilitating disease). But after some time her problem of cough and fever recurred and she was ill again. This time she was put on a 10 month
treatment course. But her in-laws did not pay much attention and there was carelessness in taking medicines regularly. This disruption in treatment further deteriorated her condition. She was admitted in LRS Institute for 4 months, and then she became better and was discharged. After 1 month she was sick again. This whole cycle repeated once again. She was eventually diagnosed with MDR-TB one and half years ago. Since then she has been on MDR-TB treatment for the last 18 months. Now she is negative and in the continuation phase of treatment. But her lungs are damaged, so she needs an oxygen cylinder to breathe.

When she is out of the hospital she needs a cylinder which costs 300 per day which her poor parents can ill afford. So she just keeps flitting in and out of the hospital where mercifully she is able to get free admittance. But the hospital administration has its own logistic problems. They find it difficult to keep a person with TB in the ward for an indefinite period of time, although they are doing their best to help her.

Rinki repeatedly told me that she felt very guilty for putting her parents to so much of trouble because of her seemingly never ending illness. No one else has TB in her family. Her father has resigned himself to his fate. He said that, “Perhaps taking TB medicine is like spraying insecticide in the body. If any germ remains, TB recurs—else why did my daughter get it over and over again?”

The Sister-in-charge of the ward said that although Rinki had become negative, but as soon as she goes home after getting discharged she starts facing problems of oxygen shortage and then she returns as they are too poor to afford an oxygen cylinder continuously. Her condition will improve gradually but for that she regularly needs nutritious and protein rich diet and fresh fruits which the family is perhaps unable to afford. Once her MDR-TB medication is over she would be prescribed some lung exercises to improve her lung condition.

**MDR-TB survivor also bravely battles against a rare genetic disease**

She is a brave woman who is a living example of the oft-quoted adage - ‘When the going gets tough, the tough gets going...’ Read her story in her own words - a real-life experience, full of grit, courage and determination, to continue living and spreading light despite seemingly insurmountable challenges.

“I have been suffering from a rare genetic disorder called Von Hippel Lindau (VHL) Syndrome since my early childhood. This disorder results in excess blood flow due to hypoxia inducible factor (HIF) resulting in repeated tumor growths in different organs of my body. VHL is a lifetime disease. Patients need to be constantly checked and treated/operated for the tumors and cysts that develop at various sites in the central nervous system and visceral organs throughout their lifetime. Because of the
complexities associated with management of the various types of tumours in this disease, treatment is multidisciplinary.

Very often timely aggressive surgical intervention is the only cure. As a VHL liver transplant patient, I have undergone and 9 surgeries one brain tumor removal, besides grappling with MDR-TB which was diagnosed in 2010. I developed MDR-TB. Manifestation of my latent TB happened under immune compromised situation, confirmed by a radiological conference facilitated by Dr Randeep Guleria at All India Institute of Medical Sciences (AIIMS). I developed pulmonary, bone and lymph involvement, to such an extent that it gnaws my bones and I walk with help of a four-toed stick.

The latest CT study of my chest reveals multiple nodules, many of them calcified, and also fibroatelectatic lesions in both lung fields. The appearance is consistent with chronic tubercular lesions. Compared with previous CT chest studies of 2010 and 2011, there is relative regression of the lung parenchymal lesions. CT study of head reveals an enhancement in right cavernous sinus as well as right convexity. In view of the size of lesion and my age (33 years), radiosurgery—cyber knife—has been suggested by doctors at Medanta Medicity Hospital.

My father’s sudden demise in 2010 has left me and my mother in a penniless situation, and my younger brother is now the sole earning member of the family. We are left with nothing to carry on my treatment. We are homeless, being evicted by landlords as and when they feel I am contagious because of my TB. At present I am living in a crummy rented place with narrow stairs, without ventilation, which is having adverse effects on my lung lesions, bone TB and hypoxia related VHL tumours which are growing fast. Initial support was provided by my friends and well-wishers but they and my brother can no longer pull the economy of my diseases together.”

Note: As of October 2013, she is struggling to raise resources enough to meet her healthcare financial expenses for a range of conditions. She is being threatened by her landlord to pay a substantial increase in rent or vacate the house...
Payel Bhattacharya – a survivor of MDR-TB who continues to struggle for health justice and her fight against VHL.

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