



GLOBAL COALITION OF TB ACTIVISTS (GCTA)

PRESENTS

CHILDHOOD

TB

&

STIGMA

CONVERSATIONS OF RESILIENCE
IN THE WAR AGAINST TB

FOREWORD BY FARHANA AMANULLAH

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We would also like to thank the brave children and parents who shared their very personal TB journeys and relived their experience of suffering and stigma in the hope that others may be spared similar suffering. We salute you and your courage.

TEAM GCTA



Activists stand up against stigma at the UN High Level Meeting on TB in New York - September 26, 2018



About GCTA



The **Global Coalition of TB Activists (GCTA)** was formalised as an organised body in 2014 to fill the gap of a global platform of people affected by TB to advocate for a people-centered, rights-based approach to TB response. The GCTA became a legally registered entity in 2018 and currently has over 300 members from around the globe.

In the past few years, GCTA has built the capacity of hundreds of TB community members across the globe and helped form four regional coalitions and one national coalition. GCTA strives to encourage, establish, mentor and bring together regional and national TB coalitions to globally collaborate on addressing issues of TB-affected communities on policy, treatment and access, leveraging complementary strengths to achieve greater and wider advocacy impact.

The GCTA envisions a 'World Free of Tuberculosis' with a mission to ensure that voices of TB-affected communities influence the global TB and health agenda.



Foreword by Farhana Amanullah

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TB-related stigma hinders TB elimination efforts. TB is treatable and curable, yet stigma can deter families from seeking care and initiating or continuing treatment. Such stigma has serious health and socio-economic consequences on children, women and families and can eventually lead to delayed diagnosis, neglected follow-up and non-compliance to treatment.

Young children, although less likely to transmit TB disease, may suffer discrimination within the family, among neighbours, in the playground and at school. Parents may suffer from feelings of guilt and shame for not being able to prevent infection or for ignoring their children's symptoms and not getting a timely diagnosis. When other household members who are the likely TB source conceal their symptoms because of stigma, they perpetuate an ongoing cycle of transmission and place vulnerable children, who can suffer grave consequences of TB, and other family members at great risk.

Adolescent females are a uniquely vulnerable population in South Asian countries; fear of rejection from potential suitors and their families affects health-seeking behaviour and may lead to death, late disease presentation, complications requiring surgery and devastating TB sequelae despite treatment. Young women with undiagnosed and untreated TB are a further threat to their newborns and young children, who are at a high risk of infection and rapid progression towards severe and fatal forms of TB. Adolescent boys in complex social situations are also susceptible to TB stigma.

The fear of loss of livelihood may prevent individuals from declaring their symptoms

and seeking diagnosis. This may result in months or years of unemployment or even precipitate death, orphaning children and directly impacting families by plunging them into further disease, poverty and undernutrition.

If the WHO End TB strategy is to succeed, all stakeholders and world leaders who join us in the fight against TB need to come together and galvanise the efforts of the GCTA and other civil society warriors. I am proud of all the great work GCTA is doing in the field of stigma, particularly in bringing to light the effects of stigma on children who have TB – an area that has not been explored or understood enough. Stigma is a strong factor preventing diagnosis among the millions of missing people and children with TB. Together, we must remove stigma from the TB narrative.

Message from Blessina Kumar

CEO, Global Coalition of TB Activists



The road map to ending TB in children and adolescents was launched at a side event alongside the UNHLM on TB last month. The figures are scary - one million children developed TB in 2017 and 233,000 children between the ages of zero and fourteen years died from TB. 25,000 children fell ill with MDR-TB, but

less than 10% of them were diagnosed and had access to treatment. Finally, in 2017, only 25% of children had access to preventive therapy.

To think that 650 children die from TB everyday, with 80% not even reaching the age of five, is heart wrenching. As a mother myself, I'm shocked to think of those mothers who never saw their children celebrate their fifth birthdays! But these are not just numbers in a report. They are Chinmay, Arina and Darina, Jackson, Mercy, Osvaldo, Adiradja, Leah and Marisa, Sameera and Ayesha, Angelina, Pamela and many thousands like them. Each story in this book talks of the extreme challenges that these children and their families went through and how they overcame them.

Just as we heard from women in our book *Women & Stigma* (<http://gctacommunity.org/?p=6503&v=3e8d115eb4b3>), stigma continues to be a barrier for access to treatment and wreaks havoc among families.

Mothers and carers in these stories tell us of how they had to crush the tablets to give their children, or of how getting a diagnosis was a challenge as the children had to have a gastric lavage done, which was painful. It would not be wrong to say we have failed our children who are our future.

We thank our brave mothers and carers for sharing their amazing stories with us so that we can bring them to the world. One thing they all share in common is they say that a support group would have helped them cope better.

We hope that these stories will not only strike a sympathetic cord in us, but will push all of us who work in TB response to accelerate our efforts to bring the quality, child-friendly diagnostics and drugs we urgently need. We hope these stories will challenge our donors to invest more in addressing TB in children, will encourage our National TB Programs to focus on children more and persuade researchers and implementers to include and not leave children behind.

Last but not the least, we sincerely hope these stories will inspire everyone to listen to the mothers and invest in building support groups so it's not a lonely journey for parents. The smallest thing will go a long way in addressing stigma and helping parents to cope better.

Let's join hands to save at least one life from TB everyday!

#lightupalife2endTB

Stigma: My Ever-Present Enemy



Chinmay Modi – a young man of twenty-five years from India, living openly with HIV – struggled to get a correct diagnosis for TB for one and a half years before he was finally diagnosed with TB in his lymph nodes when he was fifteen. He took TB treatment for a year and today, he is a strong TB/HIV advocate.

GCTA: Hello, Chinmay. Thanks for speaking with us. We first wanted to ask you – when you were diagnosed with TB, what were your biggest challenges?

Chinmay: I first showed symptoms of TB when I was fourteen. Doctors simply couldn't diagnose what the matter with me was. It took one and a half

years to detect that I had TB. Dealing with the fever, headaches and weight

loss was hard.

I was already openly living with HIV and have dealt with stigma from HIV. So I decided that I would not tell anybody I had TB because I would then have to deal with stigma from TB as well.

"I never had a support group for TB."

For me, the most difficult part was managing both the treatments at the same time – HIV and

TB. I had to take ARVs and a total of nine tablets every day after I got TB

– I found it very difficult to manage as a teenager. It really affected me psychologically taking so many TB drugs. There were no fixed-dose combinations at the time for paediatric TB.

The most challenging part was also managing while in school. I took the drugs to the toilet to ensure that nobody would see me taking the tablets, fearing they will ask me, “Now what happened to you again? Why are you taking all these medicines?”

The side effects of the medicines were difficult to cope with. I would feel dizzy and sleepy. No one understood what I was going through in class. The teachers would shout at me when I was feeling sleepy. If I took the medicines, it was a problem because I would feel sleepy. If I didn’t take the medicines, that would also be a problem.

At fifteen years of age, I was not mature enough to understand why I had to take all these medicines and how it would benefit me. At home, my parents supported me and ensured I took the medicines on time. But in school, there was no support at all.

GCTA: You mentioned it was tough

to get diagnosed for TB. That must have been difficult, but how was the journey to recovery?

Chinmay: I was misdiagnosed for one and a half years after I started showing symptoms. I finally did the Mantoux test which revealed that I had TB.

My lymph nodes were swollen and bleeding; I had a lot of pain in my underarms. I was not even able to move my hand as it would start bleeding.

Like I mentioned, mentally, I couldn’t handle taking TB medicines four or five times a day. Plus ARV

tablets that had to be taken twice a day. I couldn’t keep an alarm on the phone – I didn’t have a phone to begin with and phones weren’t even allowed in school.

Relatives would ask me why my skin had darkened so much and if I was taking my HIV medicines on time – they were convinced that the darkening of the skin and the weight loss was because of HIV.

GCTA: Can you talk a little about not revealing you had TB for fear of stigma and discrimination?

Chinmay: I didn’t tell anyone about

“I feared people could tell something was wrong just by looking at me.”

being diagnosed with TB. The school authorities never supported me when we had shared with them openly about my HIV status so I stayed away from telling them about TB.

I already faced stigma because of HIV. When I went out with my cousins, some family members would make me eat from a separate plate and would not allow me to sit with my cousins during meals – I had to eat sitting in a corner. I didn't want to face even more stigma than I was already facing.

There were many challenges in school. Parents at school would say, "You are going to die soon anyway, so why are you coming to school and spoiling our children?" Some parents were so rude, they would outrightly insult my parents by saying, "What sort of work do your parents do for you to get HIV?"

During my treatment for TB, I had high fever and diarrhoea and my friends would ask questions like, "Why is your face so dull? Why are you taking all these medicines?" They noticed that I was not moving my hand, and they would trouble me by pulling my hand and make fun of me. It was hard to deal with, and I made sure I hid the TB diagnosis from them to avoid further discrimination. You can imagine what that must have been like for a teenager.

It was only after I completed TB treatment that I told my friends and

relatives I had TB. They then asked me why I was not covering my mouth at the time or tying a handkerchief around my face or mouth – they were not aware that TB can affect other parts of your body too, apart from the lungs.

The fear of discrimination was always on my mind. I was determined not to disclose that I had TB – I would even carry the medicines in my pocket and not leave them in my bag. Sometimes in school, it was common for friends to open your bag to take out something, and I just didn't want them to see all those medicines in my bag.

I was fourteen when the symptoms began and appearances mattered a lot. I feared people could tell something was wrong just by looking at me. This troubled me a lot and I began questioning myself – I wondered why this was happening to me.

GCTA: Did you miss school because of TB?

Chinmay: I missed a week of school before diagnosis of TB. I couldn't move my hands and I was in a lot of pain. After I was diagnosed correctly, my parents went to the DOTS (Directly Observed Treatment Short-course) centre every day to collect the TB medicines for my daily treatment.

After I started treatment, I didn't miss school because the doctors ensured

they put the dressing properly and I didn't need to miss school. But I had to go to the hospital twice every day – once after school and once after tuitions later in the evening to change the dressing. In the morning before school, my mother would change the dressing and it used to hurt so badly because sometimes the dressing would get stuck and bleed.

Although I didn't miss school after my diagnosis, I couldn't take part in sports or extra-curricular activities as I was in pain and couldn't move my arms too much.

GCTA: How did your parents handle the situation? What was their response?

Chinmay: They took a lot of care, making sure I took my TB medicines on time. They didn't know I was taking my medicines in the toilet while at school. I didn't want them to know, otherwise they would start worrying about me all over again like they did when I was diagnosed with HIV when I was only eight years old.

I was not scared of anything, but I worried a lot about the psychological effect TB had on my parents. I didn't want them to worry and be disturbed – they were already thinking about it 24 hours a day. They would always ask me if I was feeling okay; it was always on their minds.

GCTA: What about support groups? Were you able to find one for HIV or TB?

Chinmay: When I started treatment for HIV in 2002, I was dependent on private treatment and was exploited. The doctor would charge Rs 50,000 (approximately US\$ 800) for meeting me for one minute. I stopped HIV treatment because of this financial exploitation.

The doctor told me that I must not go out and reveal that I have HIV – they would call the media. He would write reports and prescribe unnecessary tests and charge exorbitantly for consultation.

In 2004, when the government started giving free ARVs, I began treatment again. Soon, GNP+ (Global Network of People Living with HIV) was formed, I joined and began to speak in front of people and the government about HIV. This was my support group for HIV.

But I never had a support group for TB. This is a huge gap in TB. There is a big difference when a person affected by TB openly talks about TB; it is more effective and people will listen. To say, "Yes, I am a survivor – these are my needs and expectations from the government," is so powerful.

GCTA: What about your diet? Were you eating properly?

Chinmay: I was not eating properly but I started taking care and drank lots of milk. I started feeling better once I took better care of myself, both physically and mentally.

GCTA: What could have been done to make your experience, from the point of getting diagnosed to treatment completion, better?

Chinmay: Children go through a lot. We must do something to support kids who are forced to hide and take medication, like me taking my medicines in the toilet, due to fear of stigma and discrimination.

I don't know how many children will be able to cope with all these questions that will be directed to them. We need to provide quality counselling and explain why it is important to take the treatment, otherwise it may cause fear which will lead to discontinuing treatment.

When kids are small, between eight and eighteen years old, their mindset is such that they may forget to take medicines because they are with their friends or are busy. We need to support them.

GCTA: Do you think your experience would have been different had there

been quality counselling in schools?

Chinmay: Absolutely. We definitely need counselling in schools. Had I got proper counselling, I don't think I would have hidden the fact that I had TB and would have also understood the importance of taking my medicines on time.

Apart from counselling for children, we need to counsel the school authorities – teachers and the management. School management should not treat children who have TB any differently from other kids. They need to understand why a child who is affected by TB is not feeling well and why on some days this child will not be able to come to school. They also need to have accurate information about TB, including the larger community like the parents.

GCTA: Is there any advice you have for the National TB Program?

Chinmay: I would stress the importance of counselling for children; it is very important. We also need to ensure that schools and the overall community is supportive of children who are affected by TB, including collection of medicines while maintaining confidentiality of the identity of the family and children.

A Family Torn Apart By TB



Three-year-old **Arina** and two-year-old **Darina** are sisters from Ukraine who have been diagnosed with extrapulmonary MDR-TB. Their mother, Irina Varzova, says they got TB from their father who has an incurable form of TB and is on palliative care. Both the sisters will complete MDR-TB treatment by February 2019.

GCTA had the opportunity to speak with Irina, Arina and Darina's mother, and we bring their story to you.

GCTA: Hi, Irina. Thank you very much for speaking with us about what must have been a difficult journey for you. Can you tell us how you found out your children had TB?

Irina: Hi. Yes, this has been an extremely trying experience for us all. Arina was a premature baby and got high fever when she was three months old. The doctor we consulted asked for

an x-ray, maybe because my husband had TB, and Arina was diagnosed with pneumonia. She was treated for pneumonia for 2 weeks and started to look better physically, but when we did another x-ray, it didn't show much improvement. The doctor knew that there was TB in the family so he suspected that she could have TB too. He did a gastric aspirate and it tested positive.

GCTA: Did it take a long time for doctors to figure out what was making them sick?

Irina: It took one and a half months to diagnose TB in Arina the first time around. We refused to get Arina treated, as I was afraid of the risk of putting a small child on TB treatment. No one could assure me of how my child would deal with the aggressive TB treatment and its awful side effects, or even assure me of her survival.

Neither could anyone convince us as to why we should take the treatment, so we didn't start it. We were advised a CT scan (computed tomography test), got it done and found there was calcification in the lymph nodes. We assumed that this meant her body was able to fight the infection on its own, and therefore thought treatment wasn't necessary.

Then at the age of two, Arina was diagnosed with TB in her spine. At the same time, her eight-month-old sister Darina was diagnosed with TB in her

lymph nodes after a Mantoux test. Darina's diagnosis was quick because of the family history with TB.

GCTA: Dealing with two children sick with MDR-TB must be complicated. What have been the main challenges?

Irina: People's reactions hurt us a lot. It's very difficult to explain; many people just didn't understand and didn't show compassion when they heard about what we were going through.

I told a few friends about it but they were afraid of getting TB so they stayed away, and we only occasionally spoke on the phone.

We felt very isolated and alone as a family. Another challenge was the financial burden. I worked as a cashier in a supermarket, but I had to give it up because I needed to take care of the children. I was availing maternity benefits then and have been taking all the help I can get from charitable organisations and state welfare ever since as the financial

“The most difficult part is that... children have to be separated from their parents during TB treatment...I was asked to put her [Arina] in the sanatorium for 2 years in a different city!”

burden is taking its toll.

The entire responsibility of taking care of my children has fallen on me throughout the TB treatment. It has been very difficult to cope with.

You see, the fact that both my children were diagnosed with TB put a lot of pressure on us as parents. My relationship with my husband became very strained and we have separated and filed for divorce. TB has broken my family apart.

GCTA: So sorry to hear that. TB really does affect us not only physically but it shatters families too. Can you tell us a bit more about your experience with stigma?

Irina: I haven't told everyone that my children have TB. Half the people I did tell reacted badly; some started avoiding our family. We spoke to our friends mostly on the phone, especially during the most intensive period of the treatment.

It was only once we got medical certificates that said my children were no longer contagious that the situation improved. We started meeting our friends and our children started playing with their children once more.

GCTA: It must've been so confusing for the children to go through

something like this socially. Physically, how did they respond to the medication?

Irina: There were many side effects – skin allergies, mental reactions, sluggishness; they were not responsive when we called them.

My younger daughter Darina had more severe reactions than Arina. For example, she would just sit in one place when it was so cold outside and not move an inch for a long time.

I had to crush the pills to get the correct children's dosage as we were not given any syrup. I would add honey to the powder to make it easier for them to swallow the bitter medicines.

The worst was when I had to move away from the city where the children were taking treatment to my hometown; there were very few medical facilities there, so I had to administer the children's injections myself.

GCTA: Yes, anti-TB medicines have terrible side effects and for children it must've been even worse. Do you think that there's anything that could have been done to make TB treatment easier for your children?

Irina: I feel like the most difficult part is that in Ukraine, children have to be separated from their parents during

TB treatment. For Arina, who got TB in the spine, I was asked to put her in the sanatorium for 2 years in a different city! I refused to do so, because I felt that being away from me would mentally affect her for the rest of her life.

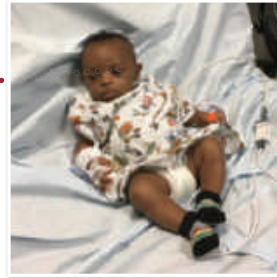
The doctors said, “We will take care of Arina, you take care of your second child, Darina”. I insisted on an alternative, because I did not want to separate my two daughters. I was lucky because the doctor went out of the way to help me given my situation – but this

happens very rarely.

GCTA: Thanks once again for your time, Irina. Lastly, is there anything you want to tell the world about TB?

Irina: Yes – TB is a very serious disease and should be given much more attention than it presently gets. It is completely curable but we need to be responsible and take the necessary action at the right time.

I Mean...Where Is The TB Vaccine?



Jackson East from the United States of America was diagnosed with TB when he was merely three months old. Delayed diagnosis nearly cost him his life, but today he stands tall as a bubbly two-year-old who fought the odds to survive. Jackson was misdiagnosed at first and had to move cities to get the right care. The family struggled to access the right medicines for Jackson and to give crushed pills to an infant.

In the following pages, we are in conversation with his mother, Kristine East, who works in the field of education.

GCTA: Thanks for speaking to us, Kristine. Tell us your story and how you found out your son had TB.

Kristine: Jackson was six weeks old when he first showed symptoms of TB. It started with him running a fever, and in two weeks the fever had escalated.

First we went to our primary care physician who prescribed the antibiotic

amoxicillin for 10 days. But the fever never went away – it hit 104 degrees F*. A baby so small with such a high temperature really scared us. To try to control the temperature, the doctors gave him a stronger dose of amoxicillin in the emergency room of the hospital.

Doctors initially thought it was pneumonia. They treated him for that and he appeared to get better...but

the fever came back.

So we took him from Dallas to Houston in search of the correct diagnosis. I was fed up – I was giving him ten medicines at one point and we were seeing three different doctors. They all knew something was wrong with Jackson but couldn't pinpoint what. Doctors also told me there was a chance that this was just a small virus; they expected him to be discharged in a few days.

It was then that things went severely wrong. His left lung collapsed and the original ER doctor we went to thought it was interstitial lung disease.

An MRI finally confirmed miliary TB in the lung and brain. All of a sudden, they came in with suits, masks, hairnets and shoes. People don't usually see TB in America (a low-burden TB country), least of all in an African-American baby who has never left the country – so this was a big deal. They isolated him in a self-contained unit and denied him any visitors. We felt like prisoners in the room.

The MRI looked like someone had sprinkled dots all over his body. He was three months old at this point. The doctors said if we had brought him in

even a week later, Jackson wouldn't have survived.

GCTA: That must've been a harrowing experience for you, Kristine. What were some of the biggest challenges you had to face?

Kristine: The biggest challenge was giving those medicines to an infant. Because he was so very young, the hospital and the doctors were unprepared. They just didn't know what to do. Every now and then, the nurses

would come and give him a total of ten different medications; since he couldn't consume them

orally on his own, they would hold his nose and stuff the medicines down his throat. They couldn't medicate him intravenously because they didn't even have these drugs available in IV form to begin with. This is still the case, and I just don't get it – I mean, how can we be living in 2018 and not be able to administer these drugs via IV?

So I had to learn how to crush the medicines and give it to him in a syrup. The medicines weren't easily available either; they had to be picked up from an organic pharmacy and there wasn't one nearby.

Reaching the right diagnosis was tough

“People don't usually see TB in America...so this was a big deal. ”

as well. In adults, you can cough out some sputum and test it. For a little baby like Jackson, you obviously can't ask him to spit. So they had to stick a tube down his throat, into his stomach. He couldn't eat for 24 hours after that – and that's a long time for an infant to not eat. Even worse, they didn't get the right sample the first time, so they had to repeat the test! I was so angry; there were a lot of tearful, sleepless nights.

Jackson never had a good night's sleep. Even today, he wakes up in the middle of the night; sometimes his temperature plummets to 93 or 94 degrees F – and it gets me thinking whether it's because of what he went through as a baby.

I have two other children at home who needed to be cared for too, and they were exposed to TB as well. They had to be treated for latent TB and they'd repeatedly complain about how bad the medicines were.

And making the three and a half hour drive between Dallas and Houston was exhausting. I eventually moved to

Houston because the treatment was just much better there.

GCTA: I can only imagine how hard and distressing it must've been. In addition to the challenge of ingesting his medicines, did Jackson struggle with anything else?

Kristine: The medication was nasty! If you are treating children, you could at least make sure the medicines taste good so that they'll actually swallow them. Like, you get grape-flavoured syrups for other stuff, but for TB – nothing. It was a nightmare, it was terrible.



The steroids made him swell up. We were told the side effects of the medicines could include nerve damage, slowed development of his motor skills and missed milestones like

walking, etc. The side effects of the medicines seemed stronger than the disease itself!

But I feel that breastfeeding helped him recover quickly.

GCTA: Absolutely. Did you face any issues around stigma from either family or community around you?

Kristine: Initially, I didn't tell anyone my son had contracted TB. I wasn't sure how people would react, and I didn't want to deal with questions like, "Oh my God! How did he get TB? What did he do?" I would lie to my friends most of the time, claiming it was a fungus or some lung disease. When I left for the Global TB Caucus event in New York to speak about Jackson's experience with TB, I had to lie again because people suddenly asked me why I was going to the city.

"We desperately need better drugs for a shorter course of treatment...Imagine...going blind trying to kill the TB bacteria!"

My mother told me that this happened to our family so that we could become strong TB advocates – never in a million years did I think I'd be a TB advocate. After we went through TB, I couldn't believe the sad state of affairs in 2018!

GCTA: Did you tell friends or relatives what you were going through?

Kristine: Jackson's TB diagnosis almost tore our family apart.

We were asked if someone in the family had TB and I just couldn't figure out who it could be. We then started

pointing fingers and it was horrible.

I first thought I had TB since I'm in direct contact with him, but I tested negative. Then we thought my husband had it – he's a police officer and there's a lot of TB in prisons – but he tested negative too. My mother works at a hospital and we thought maybe she had TB, but she tested negative. So did my mother-in-

law. Even my aunt, who works as a nurse in the TB unit in a hospital, tested negative. Trying to narrow it down to the source took so long. Everyone had to be tested with

an x-ray, blood sample, the skin test, etc.

At last, we concluded that Jackson got TB from another family member who was babysitting him while we attended a wedding. This family member was a chain smoker, incessantly coughing, and he never told anybody that he had TB. He ultimately landed up in hospital coughing up blood and had to have one of his lungs removed. He didn't survive the surgery.

I was furious. I am a mother after all and I'm only human; it's normal to blame others for my son's state. When the relative knew that something was wrong, he could have just gone for a

check-up. This is America and people get health insurance. But his choices affected everybody and we're still grieving over them. It is so upsetting it had to come to this.

GCTA: Sorry you all have had to endure so much. If I may ask, has TB put any financial strain on your family as well?

Kristine: I work in the educational field and I deal with children every day, especially children with autism and Down syndrome. Because of Jackson's illness, I stopped going to work. We moved from a double-income household to a single-income household. My husband completely supported the family and because I now lived in Houston, he bore the additional burden of paying for childcare in Dallas. We had to move out of our apartment into a new one because we couldn't pay the lease. Others would pay our bills for us because we couldn't afford to. I don't know how we weren't living on the streets; that's how bad our financial situation was.

But the principal of the school I was working for was an angel – she said my job would be waiting for me whenever I was ready to come back. I had to take

two sets of leave – I didn't go to work from August 2016 till April 2017 for roughly 6 months. There were people who were praying for me. It is at times like these you know who your true support system is. I'll never forget the two occupational therapists who would come in every day looking genuinely excited to see Jackson. Jackson was so young yet he would respond to them too.

GCTA: Is there anything you can think of that would have made TB treatment easier for you?

Kristine: Just a timely diagnosis would have helped. Children are repeatedly overlooked; they are an afterthought in TB care. And we desperately need better drugs for a shorter course of treatment – drugs that don't have the current side effects. Imagine killing your central nervous system or going blind trying to kill the TB bacteria!

Another thing I don't quite understand is immunisation – if there is a vaccine for polio, why don't we have a vaccine for TB? We are living in 2018 after all, not in the 1920s or 1940s. I mean, seriously, where is the TB vaccine?

The Lonely Battle Against TB



Mercy Wanja is a soft-spoken teenager from Kenya. She is thirteen years old and was diagnosed with TB in her lungs when she was just twelve. She went through 6 months of treatment. Through contact testing, it was discovered that a classmate in her school had TB and it's possible that Mercy and two of her friends got it from her. Mercy is also HIV positive and lives in a home for young children.

She considers herself fortunate to have round-the-clock access to doctors and nurses at the home she lives in. They were tremendously supportive during her treatment, yet she felt lonely when she had to be confined to her room for the first 2 weeks. In the following paragraphs, we are in conversation with Mercy, her guardian Sister Mary and Mkonzo, the nurse who took care of her during her TB treatment.

GCTA: Hi, everyone. We're grateful for the opportunity to speak with all three of you. Mercy – first we'd like to ask you about your story and how you found out you had TB.

Mercy: When I was twelve years old, I had been coughing continuously for over a week and was diagnosed with tuberculosis. Once we discovered that it was TB, I started treatment.

Two of my friends who live with me in the same home were diagnosed with TB along with me. One of them was eleven at that time, and the other was fourteen.

GCTA: What were the biggest challenges you faced during the time of treatment?

Mercy: Initially, it was challenging because people suddenly started treating me differently. I was all alone in my room for 2 weeks and I would just read. It frustrated me. I could not go to school during that period and I missed my friends a lot.

Mkonzo (nurse): As soon as a child is diagnosed with TB, it is standard protocol to keep the child in isolation. Once the medications kick in, these restrictions are slowly relaxed. That's why Mercy couldn't attend school for those 2 weeks.

Initially, we were shocked because three children in the home were diagnosed with tuberculosis at the same time. It was hard to identify where it came from but we soon learnt that a child in the school from a nearby slum had TB and they could have got it from her.

Mercy: But no one made fun of me when they found out about my diagnosis and everyone was very nice to me throughout my treatment. I faced no stigma.

My nurse also took good care of me and I recovered.

“I really wish I had less medicines to take, and I wish these medicines didn't have the side effects that were hard for me to deal with.”

“I could not go to school [for 2 weeks] and I missed my friends a lot.”

Sister Mary (guardian): Mercy has HIV as do her peers in the home – in that sense there is no stigma because everyone is going through the same thing and her peers are aware of TB. The dedicated nurses here are the heroes who take care of the children very well.

GCTA: Mercy, were you comfortable talking about your TB diagnosis with your friends?

Mercy: Well, all my friends were aware of my situation...but at the same time, I wasn't very keen on sharing it with them. I did not want to tell them how I felt about this.

GCTA: I can understand. And once you started treatment, did the TB medicines affect you a lot?

Mercy: Taking medicines was a challenge. I had to take 8 pills (4 pills for TB, 1 vitamin pill which accompanies TB medicine, 1 cotrimoxazole pill for opportunistic infection prophylaxis, and 2 pills for HIV) a day. I disliked taking the medicines; they would always make me nauseous. I did vomit at few times too.

It wasn't difficult to take the medicines on time since the nurses helped me and ensured I didn't miss any doses.

GCTA: Sister Mary and Mkonzo, I'd like to ask you what your biggest challenges as a guardian and a nurse caring for children with TB are?

Mkonzo: One of the challenges we face is how to deal with children and their reactions when

they are told that they have TB. They don't go to school for 2 weeks and that's when it gets difficult. It's hard but they have to be told about the consequences. They are informed through posters which help them understand better. At first, children who get TB are shocked but when they see other children following the treatment, they accept it and move on.

Sister Mary: We also have a great support system here. We have three nurses present all the time and a doctor who is on-call. She visits twice a week but can come more often, as and when needed.

GCTA: Thank you for sharing your experiences with us. Finally, is there something you can think of that would have made TB treatment easier for you, Mercy?

Mercy: I really wish I had less medicines to take, and I wish these medicines didn't have the side effects that were hard for me to deal with.

GCTA: And is there anything you want to tell the world about TB or yourself?

Mercy: All I would like to tell the world and people who are suffering from TB is to believe in God!

**** Some names have been changed at the request of the family to protect the privacy of the individuals.***

A Clinician's Experience of Working in a Challenging Environment



Dr. Rosa Herrera

Public Health Preventive Officer, Mexicali County at the Instituto de servicios de salud pública del estado de Baja California. Mexicali is the capital city of the state of Baja California in northern Mexico, on the U.S. border.

Someone once told me that tuberculosis makes adults sick from the inside out and children sick from the outside in...somehow that's true. In young patients, TB disseminates quickly, is insidious and often aggressive.

I have been close to the medical frontline for almost 10 years, and have had the opportunity to collaborate with wonderful humanitarian MDs. I've worked closely with the poor sectors as a TB manager and advocate – I've been to their houses, taken them for treatment in my car. Once, I literally picked a patient from the trash. Such experiences have shown me that the problem is not only tuberculosis. We need to tackle social determinants and health inequalities in order to adequately address TB, but we are not equipped to do this alone. We urgently need other sectors to get involved in the fight against TB if we want to win. I have been working with these

sectors looking for financial aid, food and transportation.

I think the most difficult part of working with children affected by tuberculosis is that they are not considered a programmatic priority, since they don't feed the transmission chain of TB – that reflects in the resources available for diagnosis and treatment. This group has been neglected for so many years in the fields of drug development, diagnostic tools and research that even when we have tools or drugs, they may not be endorsed for children. Sometimes we wait so long to consider children that once we have the recommendations, it can take years to grant them an accessible point of care.

Stigma Stings

This programmatically neglected group also faces stigma from many quarters. Sometimes, the school

system doesn't want them since they incorrectly think the children can infect others. At other times, their playmates' parents stop contact for the very same reason.

Plus, children depend on others for their care. TB in children is more common in poor sectors where undernutrition prevails because of economic reasons and poor care from drug-user or adolescent parents. When you face all of these barriers together in the clinic, you face the frustration of being able to meet just a fraction of the needs young ones have. The challenge gets harder when you consider that they will face the same obstacles as adults.

Children are the strongest patients; they are true fighters and they give you their heart. That's the main reason they survive. We play an important role, but we lack so many things on-field – sometimes we only have our hands, hearts and some drugs that aren't easy to administer to children.

Time To Act

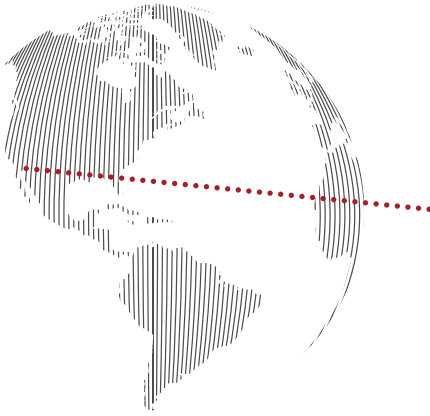
We need to take childhood TB seriously. Nobody has to die of tuberculosis, yet we do see so many kids die because of delayed diagnosis and poor care. These are not even legitimate excuses. We must include children on the priority list right now. Current endeavours like the recent UNHLM on TB give us hope, but we need action today.

Children with tuberculosis have been neglected, stigmatised and undervalued for so many years.

This is the reason I'm so glad that GCTA is bringing these stories about children with TB and the associated stigma to the world.

This is our chance to change the way we manage and care for them now. They have the very same right to health that adults do, they just don't have the resources to say it out loud.

The Deadly Hush of Stigma



Osvaldo Flores Salsedo, affectionately known as *Chualdo*, was barely twelve months old when he first started showing symptoms of TB meningitis. Within the initial 3 months he spent in the hospital, he suffered from seizures five times. Doctors thought he would not survive, but little *Osvaldo* is a fighter...and he pulled through. The seizures did, however, leave him blind, paralysed and reliant on tubes that fed him and allowed stool and urine to pass. He required a lot of care and attention from his caregivers.

Doctors were perplexed and could not get the diagnosis right at first. Because of abject poverty, his parents could not afford to do certain diagnostic tests – including polymerase chain reaction test (PCR) to diagnose TB. By the time doctors arrived at the correct diagnosis, the damage had been done. *Osvaldo* consequently spent a gruelling 6 months in hospital receiving care.

At the persistence of the doctors who treated *Osvaldo*, contact testing was done, and it was discovered that his uncle had TB and perhaps *Osvaldo* got it from him. But because of TB stigma, *Osvaldo*'s uncle neither shared this fact with anyone nor wore a protective mask. He

didn't want to feel rejected or have his community ostracise him. If he had revealed his illness and taken necessary precautions, Osvaldo wouldn't be in the position he is today.

The story does not end here. Another eleven-year-old family member got TB meningitis, allegedly from this same uncle. The boy went blind and partially deaf, and he died a couple of years later from pneumonia.

How different could the story have been for so many if only doctors had the knowledge of TB in the family earlier, we wonder?

Today, Osvaldo is four years old and has regained his eyesight. He no longer has tubes running through his body, but he still does not talk or walk.

In the following pages, we speak with his stepmother, Mercedes Martinez, who takes care of him.

GCTA: Hello, Mercedes. Thank you for agreeing to speak with us. We would like to talk about Osvaldo – how did you find out he had TB? Did it take a long time for the doctors to figure out what exactly was making him feel sick?

Mercedes: Our baby was taken to the emergency room for malnutrition and electrolyte disorder. He had been showing symptoms of TB for 3 months, but was hospitalised for 22 days without a diagnosis. After he was diagnosed, we spent an additional 6 months in the hospital. I felt that the doctors could have done much more to get to the root of the problem faster,

but because I am poor, they didn't care or want to make that extra effort. If they had diagnosed TB earlier, Osvaldo wouldn't have suffered from so many strokes and the impending disability those strokes have left him with.

GCTA: The delayed diagnosis has had unimaginable consequences for Osvaldo. Were there other unexpected challenges too?

Mercedes: The biggest challenge was the finances. I would have liked to have had enough money to have taken him someplace he could have recovered sooner. The most difficult part was not having the financial resources to give

him the attention that he needed.

We still don't buy certain items on our grocery list because we have to buy what he needs – some medicines are expensive. We look forward to the day we don't have to do this anymore, but we must prioritise his special needs.

My children love this child, as does my whole family and these small sacrifices don't matter.

We also suffer from stigma and discrimination. People on the streets stare at him and murmur; they are evidently talking about him. It makes us immensely uncomfortable as a family – the way everyone turns to see and point at him.

GCTA: It must be difficult to deal with those unwanted looks. Could you tell us a bit more about your varied experiences with stigma?

Mercedes: Apart from the stigma we've faced with my son, there is a lot of stigma in my community and neighbourhood. There are many drug users; I see people who have TB but stay silent about it out of fear. So I am always providing information about TB, trying to encourage people to go to the healthcare unit when I see the symptoms.

GCTA: What were the effects of the TB medicines on Osvaldo?

Mercedes: He used to vomit and couldn't eat sometimes. The medicines made him really nauseous, but he was very strong. He slowly but surely got better and his condition improved.

"I see people who have TB but stay silent about it out of fear."

GCTA: How was his diet during TB treatment?

Mercedes: He had lost a lot of weight. I fed him

a special homemade smoothie with vegetables and cookies so he could regain the weight he had lost. It took a year for him to attain adequate weight.

GCTA: Did you feel comfortable sharing what Osvaldo was going through with friends or relatives?

Mercedes: My family whole-heartedly supported us every step of the way. When I tell acquaintances though, I do have to explain details about TB meningitis because I feel that it's necessary to say that it is not contagious. People will sometimes congratulate me, lauding how I have held it all together so far. But I'm not bothered about dwelling on whatever I have lost – till the time Osvaldo needs my care, I will be with him...until the last day.

GCTA: How does the TB diagnosis affect him even today, after recovery?

Mercedes: Whenever I take him for medical services, he is treated with care and respect. There are plans to operate upon his spinal column and tendons but doctors say that he will never walk again. Nonetheless, we are positive that the situation will improve. He has demonstrated amazing strength and determination, and we will take him to an NGO called 'Life in Motion' to receive therapy.

GCTA: Is there anything you can think of that would have made TB treatment easier for Osvaldo to bear?

Mercedes: Our appointments were scheduled far apart. We should have been given appointments for neurology and pediatric services every month, as far as I know.

I could have been paid a little more consideration too. I waited outside the hospital all day. I was permitted to see him only on Saturday and Sunday. The staff would not let me see him because

I was his stepmother – it was really hard since I am the one who cares for him.

GCTA: What was your biggest challenge as a parent caring for a child with TB, Mercedes?

Mercedes: A significant challenge was posed by the TB medicines themselves – I had to be aware of the many medicines I needed to give him. He could not even swallow the medicines because of his disability resulting from the seizures. Dealing with the side effects of the TB medicines was so hard because the medicines made him vomit a lot.

My biggest ongoing challenge is his inability to walk, but I'm willing to take him wherever I can to ensure he gets the help he needs to get better. I want him to be a normal child again.

It is also hard for me to work and care for him at the same time. I am tired. But I love him. So it isn't an unbearable struggle for me.

GCTA: Speaking of work, did you have to miss work because of Osvaldo's treatment? How did you manage to juggle everything?

"If they had diagnosed TB earlier, Osvaldo wouldn't have suffered from so many strokes."

Mercedes: My boss allowed me to arrive late. I may have missed some hours but I've never completely missed work. Also, Osvaldo's real mother sometimes helps take care of him while I work.

GCTA: Thank you so much for your time and candor, Mercedes. Lastly, is there anything you definitely want the world to know about TB?

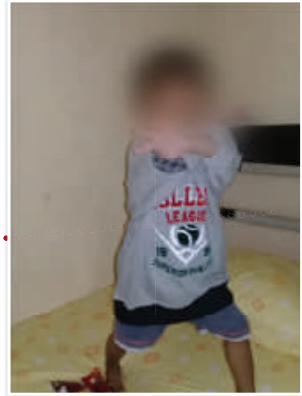
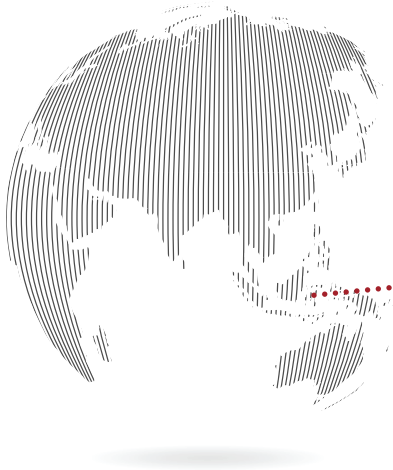
Mercedes: Tuberculosis is contagious only if it is in the lung. TB meningitis is not contagious. If you have TB in

the lungs, be extra careful with people around and ensure that you maintain good cough hygiene.

I think there would be a great difference if people took the right precautions and maintained proper hygiene so that TB does not spread. We need to ensure this!

**** GCTA would like to thank Dr. Rosa Herrera for facilitating this conversation and for her valuable inputs into this story.***

TB: The Money-Guzzling Monster



Adiradja Bima is a four-year-old from Indonesia diagnosed with Tuberculous Spondylitis. When we interviewed his mother in August 2018, he had been receiving treatment for a little over a month; unable to walk, he was recuperating in the hospital.

Adiradja's mother, Yuni Prastika, reveals that although hospitalisation and TB treatment (which, at the time of publication, was still underway) is free for them, her husband has had to stop working in order to take care of their ailing son.

The financial strain has been a huge burden on the family who is having trouble coping with the expenses of everyday living.

GCTA: Hi, Yuni. Thanks for taking the time to speak to us while still in the middle of Adiradja's treatment. Could you tell us how you discovered he had TB?

Yuni: Hello, thanks for the chance to

share our story.

A little over a month ago, Adiradja had a high fever, his abdomen was distended and he could not pass urine or stool. He complained of severe weakness in his legs and we admitted

him to hospital soon after. Doctors did an x-ray of his abdomen, a sonography and an MRI (Magnetic Resonance Imaging). He also underwent an operation in his back – a laminectomy. The biopsy report tested positive for TB.

The diagnosis took one month and the doctors didn't suspect TB at all at the beginning. We were quite surprised with the results.

GCTA: After such a shock, what have been the biggest challenges along Adiradja's path to recovery?

Yuni: We are currently in a very stressful situation – he could walk before but now he can't. He can't even move his legs.

It worries me; the progress is very slow...I don't know if he'll be able to walk again.

But my biggest challenge is that, as a mother, I have to stay for a long time in the hospital. Adiradja is not going to school at the moment since he got sick a month ago. Since then, my husband has also stopped working to take care of him. He is a chef in a restaurant and hasn't been able to go to work given Adiradja's condition.

GCTA: With your husband not working, has TB put any financial

strain on your family?

Yuni: Luckily for us, the hospitalisation and TB treatment is free because of insurance. So we don't have to worry about medical expenses. But for everyday living, we are struggling because there is no income coming in anymore. It is a big problem; I don't work either.

GCTA: That must be hard for you. Did you tell friends or relatives about Adiradja's illness?

Yuni: Yes, I did tell my friends and relatives. They were all very surprised. It's a rare condition and everyone was wondering how he got it. I did not experience stigma though.

GCTA: That's refreshing to hear. Is there anything you can think of that would have made TB treatment easier for Adiradja?

Yuni: Yes, we had to wait for a month to do the surgery and get the correct diagnosis – I feel it could have been done sooner.

My son has drug-sensitive TB, so luckily he hasn't had many side effects yet. He is doing okay as far as taking the medicines goes. No challenges in that respect.

GCTA: We hope the rest of Adiradja's

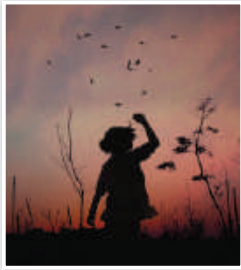
treatment is hassle-free, Yuni. Finally, is there anything you want to tell the world about TB?

Yuni: I think my son got TB from a roommate in the dormitory where we live. She had a chronic cough and my son used to be around her.

I would appeal to everybody to please be careful if you have a chronic cough and get medical treatment as soon as possible if you show any TB symptoms.

“For everyday living, we are struggling because there is no income.”

Imprisoned by TB



*This is the story of two sisters from Kyrgyzstan – thirteen-year-old **Leah** and nine-year-old **Marisa**. Their mother, Donna, was the first to be diagnosed with MDR-TB and contact testing revealed that her young daughters were affected by MDR-TB too. Donna did not get to see her children for 6 months because, as per protocol, she and her children were admitted to different hospitals. Read on as we converse with Leah, Marisa and Donna.*

GCTA: Hi, everyone. Thank you very much for agreeing to speak with us about what must have been a very difficult journey for the family. Leah, can you tell us how you found out you had TB?

Leah: I got TB from my mother, who was diagnosed with TB in her lungs. Three days after my mother got a fever, a chest x-ray was done which revealed she had TB. The next day, my

sister Marisa and I got a Mantoux test for TB done. My results were negative for TB with that test, and my younger sister tested positive. But when I did a chest x-ray, it was positive for TB. We soon learnt it was MDR-TB. My sister and I have completed our short-course therapy and our mother is still on treatment.

GCTA: Dealing with MDR-TB must have been very difficult. What were

the main challenges?

Leah: For me, it was very tough to take those TB medicines. In the beginning it was easier, but towards the end of the treatment it was so hard to swallow the drugs because of the side effects. I just couldn't handle the nausea and vomiting.

I also got incredibly bored in the hospital. There was nothing to do, though the people there were good to me. It was difficult to stay in the hospital for so long; I just wanted to go home.

Marisa: Yeah, me too. I thought I'd never get out of the hospital; I was there for so long.

And when I took the medicines I wouldn't feel good – I would feel like vomiting and sometimes I did.

Donna (mother): The biggest challenge for me was to accept that I couldn't see my children for so long – I didn't get to see them for 6 months because the doctors did not allow us to meet each other. The separation was harder to endure than the treatment itself. We have always been together. I couldn't wait to be cured of TB and meet them again.

Leah: It was very hard for us to be without our mother. At the same time, we had to deal with the side effects of the medicines and we were not allowed to go out of the hospital. My sister and I were in the same room. While I was going through my own TB treatment, I was caring for my sister who was suffering through hers.

Donna: Another challenge I faced was my loss of appetite, so I wasn't eating properly. But as far as the medicines go, I didn't experience side effects or face much difficulty in the hospital.

“It was difficult to stay in the hospital for so long; I just wanted to go home.”

GCTA: I can only imagine how painful the separation must have been. Leah and Marisa, did either of you miss school because of TB?

Leah: My sister and I missed 6 months of school since we had to be in the hospital the whole time. We underwent TB treatment for a total of 9 months.

I tried to continue studying while in the hospital. I didn't find this difficult – I passed the exams once I was discharged from the hospital. The difficult part was taking the medicines.

But I missed my friends a lot while I

was in the hospital. Just a few of them visited me while I was admitted, and not often.

GCTA: Tell us more about your experience with stigma. Did your friends start treating you differently once they found out you had TB or when you restarted school, girls?

Leah: I didn't face any stigma from my friends or classmates. They treated me the same, like they did before I got TB.

Marisa: My friends did treat me slightly differently once I went back to school. Some classmates didn't even recognize me; I had been away from school for so long that they had forgotten me. But when my friends found out I had TB, they didn't run away from me or anything.

Donna: I told Marisa and Leah not to tell anyone they had TB. I didn't want anyone to know and start gossiping about them. I was worried that people would start thinking that my children would infect them with TB.

So at the beginning, only my husband and children knew about our diagnoses. But later, people somehow found out.

As a mother, I was just worried about all of us being sick with TB.

GCTA: Dealing with TB can be emotionally and mentally trying. How did you feel when you got diagnosed and subsequently treated for TB?

Leah: I cannot even begin to describe how badly I behaved after I was diagnosed with TB – I would cry all night. I started blaming the whole world for the state I was in; I was so angry. I also had a lot of fear of being in the hospital so I used to resist going there. It was not easy.

“I started blaming the whole world for the state I was in.”

Donna: I felt bad and blamed myself that my children got TB.

GCTA: Leah, how did your father handle the TB diagnosis?

Leah: My father was very nervous but was extremely supportive. He visited us every day in the hospital and yet didn't miss days at work.

Donna: Yes, he would visit both the hospital I was admitted in and the one the girls were admitted in every single day. He would bring us fruits. My husband is the sole breadwinner of the family; he had to cook for himself because we were all hospitalized.

GCTA: It is sad to hear the extent to which TB has affected your whole

family. Did you have any support groups to help you during your TB treatment?

Leah: No. It would have been nice to have people to talk to about TB. I would definitely have felt less lonely if I had the chance to connect to other peoples' experiences as well.

It would help if there was quality counseling in schools too. My school had a lecture on TB 3 years ago, but that's it.

GCTA: Thank you for those suggestions. Do you have any advice for the National TB Program?

Leah: I am thankful for the free drugs I received, and I am also thankful to the doctors who treated me. I would like to tell the National TB Program that being in the hospital for so long was difficult, and it was very boring because there was nothing for children to do.

Donna: I appreciate the doctors and nurses who treated me. I hope that everyone gets TB diagnosis and treatment on time. And parents and children should not be separated during TB treatment – if I got my treatment along with my children, it would have been easier for us.

Marisa: I don't want anyone to suffer from TB. That's all.

"I had been away from school for so long that [some of my classmates] had forgotten me."

**** Names have been changed at the request of the family to protect the privacy of the individuals.***

Ignorance Is Never Bliss



Sameera and **Ayesha**, sisters from Pakistan, have both been diagnosed with TB. The older sibling was the first to contract it. After struggling to get the right diagnosis for a year, TB put a huge financial burden on the family. In order to pay the mounting medical bills, they were forced to sell everything they had. Despite doing this, they were forced to take loans to pay for treatment.

Fourteen-year-old Ayesha's treatment is ongoing and her parents can no longer afford to provide adequate nutrition. In the following pages, GCTA is in conversation with Ayesha and her mother, Ameena Kazi.

GCTA: Hi, Ameena. Thank you for talking to us about your family's battle with TB. Could you please tell us what this was like?

Ameena: It started with our elder daughter, Sameera. She was severely ill. We took her to multiple hospitals

in Sultan, Chiniot and Nazimabad but doctors were not able to figure out why she was so sick. We got to the point where we had lost all hope of her recovery. We had visited so many different cities in desperation until we finally found out she had TB. This took an entire year.

“By the time they felt strong enough to resume classes, they had lost a full year of school.”

So when our younger daughter, Ayesha, fell ill, I was very worried. I believed that she too had TB. To clear my doubts, we took her to the same hospital where Sameera was diagnosed and treated and the results confirmed that Ayesha too had TB.

We didn't want Ayesha to go through the same struggles that Sameera had, so we took extra care to ensure she was correctly diagnosed and treated. Our experience with Sameera helped reduce the delay in treatment.

Without thinking about the financial difficulties we knew we were going to face, we started treatment right away. Sameera's recovery gave us hope that Ayesha would recover too.

Our biggest challenge was getting the correct diagnosis for Sameera and then dealing with the financial strain TB put us through. Each time we were given the wrong treatment, we lost money and her health deteriorated. It got so bad; we had to take loans in order to take her to different hospitals in different cities.

First, we sold the only piece of land we owned and moved to a rented house, but that wasn't enough. We were forced to sell our only source of livelihood – the taxi we owned – to complete our daughters' treatments. We tried, despite the lack of finances, to ensure our girls had a good diet during their treatment.

We lost a lot of money and have not yet recovered it all, but I'm thankful to God and the doctors who treated my girls at Indus Hospital that they both are healthy again. I don't regret losing our

property and money – money comes and goes – but I feel sad when I am sometimes unable to provide healthy food for my children.

GCTA: Did you face any stigma in the middle of all this? Did you tell your friends or relatives that the girls have TB?

Ameena: Our relatives knew that the girls were not well but we did not openly tell them that it was TB. However, they had a feeling that it was TB, and we could see a change in their behavior. We tried to protect the girls, but Sameera and Ayesha also noticed that our relatives were behaving differently. We just ignored them and focused on their treatment. Eventually, post-treatment, our relatives were surprised to see that the girls recovered so quickly.

GCTA: Did either Sameera or Ayesha miss school because of TB?

Ameena: Yes. In fact, they both lost a complete year. We had no choice but to take Sameera to different doctors in different cities to get to the bottom of what was making her sick. So she was not able to attend school during that time. Both the girls were too weak to go to school during treatment. By the time they felt strong enough to resume classes, they had lost a full year of school. We are trying to get admission

again.

GCTA: It is very sad that you missed a year of school, Ayesha. What was your biggest challenge with TB?

Ayesha: When I was sick, I wasn't feeling hungry. Once I started taking the medicines, I got my appetite back. Taking medicines was the easier part.

Ameena: Ayesha braved the treatment and took the medicines on time. Her sister's journey gave her strength and the hope that she too could recover from this disease.

GCTA: Ameena, were you able to find any support groups for TB?

Ameena: No, we were not aware of any support group that could help us. There is an appalling lack of awareness about TB in our community. We did not openly share our daughters' tryst with TB with our relatives, but if somebody shared their story with us, we would counsel them and ask them to start treatment at the earliest.

GCTA: From the point of diagnosis to completion of treatment, what could have made your experience better?

Ameena: Timely and accurate diagnosis would have been tremendously helpful. Sameera suffered because of lack of proper diagnosis. But we got

the full support of doctors during the treatment.

GCTA: Do you think there is need of spreading awareness among people, specifically among teachers and students in school?

Ameena: Yes, it is crucial. People lack awareness about TB. Schools can play an important role. Spreading awareness among teachers and students would be really useful so that they are better equipped to handle a situation when a child has TB. At the same time, it is important to tell people that it can be cured. Once TB is diagnosed, the right treatment can be given.

GCTA: Lastly, do you have any advice for the National TB Program?

Ameena: The National TB Program should focus on spreading awareness and facilitating early and correct diagnosis. If a child is not eating properly or is weak, it is important to find out the reason behind this behaviour. Medical checkups must be done immediately, followed by correct treatment, so they can recover fast.

I cannot stress enough the importance of right diagnosis and timely treatment, especially for small children. They are very delicate and vulnerable. Parents should know that even if children get TB, it is a completely curable disease when correctly treated.

*** Names have been changed at the request of the family to protect the privacy of the individuals.**

Stigma Spares No One



Angelina Grab is a nine-year-old little girl from South Africa who suffers from an auto-immune disease. She was diagnosed with pulmonary TB when she was two years old. Angelina's mother, Janet Grab, says it was difficult to give the 'grainy' TB medicines to a toddler and faced challenges in keeping her child in school. A pharmacist by training, she took pains to educate and sensitise those around her. GCTA chats with Janet to learn more.

GCTA: Thank you for sharing Angelina's story with us, Janet. Please tell us how you found out your little girl had TB.

Janet: My daughter had TB when she was two years old. She suffers from Common Variable Immune Deficiency (CVID) and was receiving immunoglobulin at the time. She had recurrent pneumonia and wasn't gaining any weight. To help you

understand what I mean by not gaining weight – she weighed 8 kg when she was one year old and when she turned two, she weighed just 8.3 kg. In this fragile state, she had a fever every night for a week and night sweats. A chest x-ray revealed lymphadenopathy which is usually symptomatic of TB.

She had indeed contracted TB, but we had no idea where she got it from. Contact testing was done in the family

and it was negative. But doctors were very sure about her diagnosis.

We didn't face much of a delay in diagnosis as is usually the case with TB. She was sick from other illnesses as well which were being treated, so one discovery led to another and we found out she had TB within a month.

“When I told the principal of Angelina’s school that she had TB, she was shocked and asked me to not tell anybody about it.”

dissolve the tablets, which were red in colour, to give it to her. They were grainy and she would try to spit them out. She would fight and cry, and then run away. I always had to bribe her with some candy at the end of it.

I didn't notice any side effects of the medicines however; I think she did okay.

She wasn't behaving like your typical two-year-old. She was lethargic, she wasn't growing; she didn't want to do any activities. She would go to the playground and sit in the corner. She was very quiet and she cried a lot; she wasn't eating or drinking much – it was a huge problem.

GCTA: It's a relief to hear that the TB diagnosis did not take too long. Were there other challenges as well?

Janet: Yes, school was the biggest challenge. I had to show them reports and a letter from the doctor to confirm that Angelina posed no risk to other children in the school.

Giving the medicines to a toddler was also very tough. She was on so many medicines at the same time. I would

GCTA: Yes, administering treatment to young children can be a real uphill task. Did you face any difficulty accessing TB treatment for Angelina?

Janet: It was better than I expected. In South Africa, we access TB treatment in the government hospital. You simply have to register yourself with the Department of Health. But the complication was that with Angelina, her immune system was so weak, we were concerned about her picking up other diseases there.

The healthcare system is usually not flexible at all. But since I was working in the system, I insisted on an alternative for Angelina. I would weigh her at home once a month, go to the hospital alone with the weight and get the

necessary medicines.

GCTA: It's great to hear about your positive experience. Was Angelina eating well during TB treatment?

Janet: Not at all – she ate very poorly. She would have the PediaSure supplement. I feel like she's alive because of PediaSure.

GCTA: Janet, you mentioned earlier that school was a challenge. Did Angelina ever have to miss school because of TB?

Janet: She didn't initially. But while taking TB treatment, she missed 3-4 months of school in

between because she was unwell with bronchitis and the doctors recommended that we take her out of school for her own wellbeing.

GCTA: And did you ever have to miss work? Was there any financial strain on your family?

Janet: I missed a week of work at first. Then I had to visit different clinics and take time off from work in the morning. But I would make up the hours at a different time in the day.

GCTA: Could you tell us a little about your experience with TB stigma?

Janet: TB in children is different from TB in adults. Angelina didn't cough at all. When I told the principal of Angelina's school that she had TB, she was shocked and asked me to not tell anybody about it. She was worried that the other kids would pull out of class and stop attending school. Being a healthcare professional myself, I could confidentially address her concerns. I got a certificate from Angelina's doctor

and brought the principal material on TB for her to read, and she agreed to let Angelina come to playschool.

I tried to tell as many people as I

could to dispel the stigma. I did all I could to explain that 'Yes, Angelina has TB, but she doesn't pose a threat to your child for all these reasons'. I think I was successful. People were nervous at first but once they noticed she was not coughing, they were okay.

GCTA: Did you tell friends or relatives about Angelina's TB diagnosis?

Janet: I did tell people, and they were shocked. There is grave inequality in South Africa. The stigma around TB leads people to believe it is a poor

"The stigma around TB leads people to believe it is a poor man's disease."

“Extending this [flexibility] to all parents would make them feel...that their child is not just another statistic or number in a book.”

man’s disease, least of all to be associated with a white family.

GCTA: Were you able to find a support group to help you through your daughter’s journey?

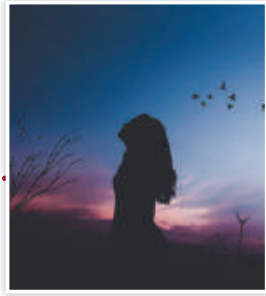
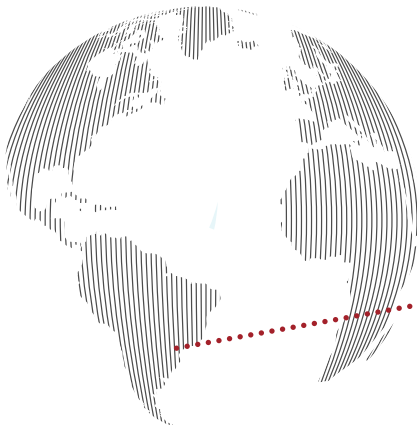
Janet: There was no support group at all. It would have been good to interact with other people who could share tips on how to give the TB medicines to a baby, and provide other support as well. It would have been a huge advantage.

GCTA: Thanks once again, Janet, for opening up to us. Lastly, is there any advice you have for the National TB Program?

Janet: I’d say my experience of having flexibility is very important. Extending this to all parents would make them feel like you are genuinely interested in providing quality care, and that their child is not just another statistic or number in a book.

Also, the colour of the medicines change every month, so healthcare providers need to take time out and clearly explain those changes to parents to avoid double dosage. They need to take time out to listen to moms.

The Hard Truth



Pamela is a fourteen-year-old girl from Pavuna, a small neighbourhood on the outskirts of Rio de Janeiro, Brazil. A typical teenager, she loves going to parties and hanging out with friends. After she was diagnosed with cervical lymph node TB, she found it difficult to share what she was going through with friends and family for fear of discrimination and prejudice. GCTA caught up with Pamela and her mother, Rosana P., to learn more.

GCTA: Hi, Pamela and Rosana. We're glad to be able to speak with you. Please tell us your story – how did you find out you had TB, Pamela?

Pamela: I had a tumor on my neck for a long time. It took a long time to diagnose it as TB.

GCTA: After diagnosis, what were the biggest challenges along your path to recovery?

Pamela: Well, my life changed, and I was upset.

It was hard because I was nauseous a lot. So I took the pills only when I wanted to. I didn't take my medicines on weekends because I wanted to drink vodka at parties, and this harmed the effects of the treatment.

GCTA: Well, teenagers are the same everywhere! Is there anything you can think of that would have made

TB treatment easier for you?

Pamela: I don't know, maybe the same thing. It doesn't matter...Wait, I just thought about it – the pills would help get rid of this tumor on my neck.

GCTA: Rosana, as a parent caring for a child with TB, what were your biggest challenges?

Rosana: I had already told her about the illness she has. Also, I did not want her to go to her uncle's house; he was HIV positive and had pulmonary TB.

GCTA: Did TB put any financial strain on the family? Did you ever have to miss work?

Rosana: No, I didn't have to miss work, but it changed my routine. I needed some money to go to the doctor and buy the pills from the health centre. You know... I had to implore her father for money to buy the bus ticket. It was awful!

GCTA: And did you miss school because of TB, Pamela?

Pamela: Yes. I missed classes for one month when I was in hospital as they investigated my symptoms.

GCTA: Were either of you

comfortable telling friends or relatives what you were going through?

Pamela: No, I didn't talk to anybody. Whenever someone asked about my problem, I told them that I didn't know anything about it.

Rosana: I told people about our situation – I don't have any shame about it. But friends and relatives started looking at Pamela differently.

"I didn't tell anyone about my TB because I was scared that people from our community would avoid me."

Pamela: I didn't tell anyone about my TB because I was scared that people from our community would avoid me.

Rosana: There is still a lot of stigma around

the disease in Brazil, especially in poor areas.

GCTA: Thank you for sharing your experiences with us, Pamela. Lastly, what would you tell other children going through what you went through?

Pamela: If a friend asked me about tuberculosis, I would admit to him or her about my problem. But I wouldn't want to talk about my personal experiences regarding the treatment. I wouldn't say anything.

"The GCTA book on childhood TB and stigma offers us an intimate view into the challenges children and families affected by TB face, and how they manage to cope with and overcome the many struggles that can follow TB diagnosis and treatment. For children, getting a diagnosis is often a struggle in and of itself. The interviews included in this series highlight areas where we can and must do better for children and families with TB."

- Lindsay McKenna (USA), Treatment Action Group (TAG)

"I cannot imagine a more difficult situation than the plight of children who are going through MDR-TB treatment. GCTA's book on Childhood TB and Stigma is an important publication to be read by all in the TB response to understand the depths to which TB stigma affects children and their families. These stories of children facing TB and stigma calls for greater urgent action and support from the global community to an aspect most ignored and neglected."

- Gracia Violeta Ross (Bolivia), Board Member - Global Coalition of TB Activists,
President – Bolivian Network of People Living with HIV/ AIDS

"Children affected by TB are vulnerable, but they do not get the attention they deserve. Children cannot speak up on their own behalf; they need us to make sure they get treated properly and to create an environment with no stigma. Do not let TB steal their dreams, for they are our future. The GCTA TB Stigma stories, first about women and now about children, are valuable resources to understand first-hand how stigma is a huge barrier to access and can also tear families apart."

- Elvi Siahaan (Indonesia), Board Member - Global Coalition of TB Activists,
Country Director – Yayasan Menara Agung, Pengharapan Internasional