# TB PRODUCTION A HIDDEN NIGHTMARE

#### Chulu

Molweni! (Hello)

With me are my colleagues and we would like to share with you our experiences and lived stories infected and affected by TB. That's if you'd allow us....

# Owen speaks...

a creedshaw story out of a very dark place called life, the theory of the world depopulation was wilding that time until something came up & became a threat to humanity. A hidden nightmare! bathi (they say), a new disease was announced by a Dr Robert Koch on March 24 1882, the discovery of mycobacterium tuberculosis. (TB)!

Le (this) tuberculosis is an infectious monster that I survived! It mostly affected my lungs & it is said to be caused by a type of bacteria. I can imagine what's going through your mind right now, does that mean, we can't sneeze, cough or spit? Times & generations went by & le(this) tuberculosis continued to conquer & divide humanity, was it that people did not pay enough attention? and maybe i was one of them.

Okay let me break this down for ya'll, on the 27th of june 2018, mhhhhhm the 27th of june 2018 i started to feel something really weird, I had a really bad cough that lasted 3 & a half weeks & throughout those weeks I had night sweats that were draining my energy, the longer I coughed & sweat, the weaker i became, I was scary! I started to lose appetite & weight, I really believed that i had fever, it was just fever.

three weeks later on the 23rd of july things started to hit up even more as I woke up 10:00 am on the dot after I having a sleepless night, I started to cough out blood & thought I should see a doctor because this was not a normal fever I thought it was.

on the following day the 24th of july I woke up at 7:30 am and got ready with my brother steven to go to my nearest clinic in Khayelitsha. Let me paint you a picture, clinics & hospitals in Khayelitsha are very uwelcoming, i felt fear as soon as I got into Dr J. Smith's consultation room, I started to panic as I witnessed other patients conditions & I heard her voice, " goodmorning sir, please try & calm down, how can I help you today? " her voice was so soft & comforting, it gave me hope & light into this situation I found myself in, I couldn't even respond to what Dr. smith was saying because I was so weak my whole body was stiff & I had a really bad cough too.

My older brother was with me, he took over for me "goodmorning doc, my brother's been sick for like 3 weeks, he's been coughing & after a week he had night sweats that affected his energy & appetite & lost weight, so yesterday he started to cough out blood & thought we

should.... " dr smith quickly interjected & said "tuberculosis" denial & stigma jumped into my head, denial that brought negative thoughts about the situation, my quickest thought was, now I have to keep away from my family, my girlfriend, my friends! So I asked myself questions like, "why didn't I take the cough serious? Why did I avoid it? am I going to die? or am I going to beat this monster?

"Its okay sir, everything will eventually be fine, Mr harrington here managed to complete the Tuberculosis symptoms list that includes, weight loss, loss of appetite, coughing blood, night sweats, weakness & fatigue, I don't even have to test him to see it, i think its pretty obvious to me, but we'll have to test him to really confirm it! & see if it has not graduated to MDR or XDR " the Doctor continued. At that time everything was very confusing, I struggled to understand what MDR or XDR was I could'nt even ask because I lacked the energy & all that was new to me, but I knew that I never wanted any of those things at all.

Things got serious, Dr smith suggested I be admitted and be transferred to KDH Khayelitsha District Hospital. This was because the clinic lacked space & enough medication, so my brother went home to inform my family & friends of these news & left me at the hospital.

As I thought the information got out after 2 Itwo days of being admitted at KDH, I come out of a very judgemental community where some of my neighbours had harsh comments about my whole situation, even though they had no idea of what I was going through.

# Wanga speaks...

In the heart of the Qumbu village, now Qumbu is one of our villages in the Eastern Cape. My family is from there, our roots. In that village a community hero was raised, Zongezile Nohayi, my uncle. He was a hardworking member of the community council, 29 years old with a dark coloured sharp face and tall as any man could be, I guess I got the height from him.

He was the tall village tree where everyone who needed any kind of help in his village found shelter. Young boys would even call him when they can't reach a tree for fruit. He was known as a hero the day he put an end to crime-related matters in the village. Zongezile Nohayi was his name.

Like any other day, he was doing his round helping here, fixing that, sharing a story there. Did I mention he was funny, hilarious because dealing with stubborn old men and their customs isn't easy at all. One needs a tad of a sense of humor. So they were helping one of the villagers cattle that was trapped just outside the village fields. They say as they pulled the rope he slipped, fell off a cliff and broke his arm. No big deal he joked as they rushed him to a nearest hospital which was then a 2 hours drive outside the village. Tests were run and they found out a sneaky bacteria came in and destroyed a hero's life. It was said that Zongezile was living with a TB bacteria for approximately 3 years and he had no idea a hidden nightmare indeed.

The family had hope that he would beat the disease as the hero he is, until this one mysterious doctor came and informed everyone that he was diagnosed with the extreme stage of TB, XDR. These terms! these words! No one understood them and so fear spread the village like a grass house on fire. "who's next the villagers asked each other in fear" And just like that my uncle's life ended because of a mysterious disease that no one understood.

#### Chulu speaks..

Imagine a 8 year old boy from Harare Khayelitsha/ ekasi, a township where people had little knowledge about any kind of disease forcibly introduced to Tuberculosis. Yes, that little boy was me.

Our school didn't touch on these kinds of events. My mother or family members were throwing questions and answers around, no one knew what was wrong with my brother. I witnessed my brother suffer, coughing nonstop. Why him, why now? Maybe God knew, so prayer sessions were held. It all didn't make any sense, my mother would cry. My son is a person who is always at the gym and he stays in shape so he is active/healthy. I would listen to my uncle trying to convince my brother that it will pass.

It was a fever we all said or maybe a flu. Then he'd be up all night long and his bed would be so wet that you would think it was raining inside the house and he was getting thinner as the days went. At this point people in the community said he had HIV, and yes a part of me believed he was.

He started coughing out blood. It was scary, he couldn't breathe properly, this was it we all thought we were going to lose him. So mother made the call to the day clinic and he was admitted, he was later diagnosed with TB, a hidden nightmare.

## Spha speaks...

I grew up on the dark streets of Khayelitsha. I love boxing, it keeps me busy and focused. My favorite boxing star is Landile `` man-down " Ngxeke, a global champion known for his knockouts. So being physically fit and out of the streets is a lifestyle I chose.

One time my best friend and I hid from one of the boxers because he was my toughest opponent and our coach liked making us spare. We lay low for a while until later on, there was a knock on our academy door, and a new member came his name was Thato. The focus shifted from us and everyone welcomed him as one of our own. No one bothered to ask where he was from, his background nore why he was joining boxing but something was definitely not ok with him health wise.

Time passed and months went by with him at the academy until weird things started happening. Thato started coming to the gym less, maybe twice a week or not at all. Our coach got worried and asked him what's going on and he'd never respond. A month passed, Thato stopped

coming to the gym and we asked ourselves why, with no answers, my best friend and I went looking for him, it wasn't easy because we didn't have his address. Eventually we found his house and found out he lived with his mother who we witnessed holding her chest and complaining about chest pain and coughing blood.

That shook us, we did not know what to do or what was going on at that time so we left to go find Thato and just as we were giving up we saw him at a car wash cleaning a car. Still in shock I told him his mother was getting weaker and that we saw her. He didn't mind us and continued with the car. We carried on asking why he was at a car wash, he said he is finding ways to have money for his mother to eat something before taking her pills.

There was a moment of silence, I asked him if he knew what was wrong with his mother and if she had been to the hospital? Still cleaning the car with the other hand scratching his body suspiciously, he answered TB they say and no! And said what's the point, she won't get any help there anyway. We noticed Thato had unusual red bumps and he looked frail, and what about you I asked have you gone to get checked out. He just gave us a blank stare, the coach had to hear about this. As we rushed back to the Academy we were convinced whatever was going on with Thato and his mother was a hidden nightmare, witchcraft.

# Everyone....

And here we go again....a never ending nightmare, forever left with scars by the pain and torture it carries with. A hidden nightmare lifetime lost, mindlessly questioning, siphikisana (arguing) aimlessly in uncertainty. Why him, her, them... it's gray, I can not tell yet it's somehow shared and socially accepted systems and actions...it is Tuberculosis....

# Owen speaks...

I survived it! In the three months I was discharged from the hospital my family, friends and community supported me through that difficult time, i felt love, i felt support & most importantly I felt Us being one as a people! That really brought me back to life.

# Chulu speaks...

Our communities are starved of inclusion, could it be by design, are we allowed to forget who was taken mysteriously, did I mention it feels safer now with zero human interaction, what's the point when we are washing away with no connection and no reaction. It is indeed a hidden nightmare, a dream state where our demons rise, killer symptoms, no clear reason, no time for any breathing, how do you identify it if it's hidden? Do you cry? Do you listen? or it won't matter in the end, for without the knowledge and information of when, where and how a last breath with a permanent decision to forever fight for life will be taken...are we allowed to forget who was taken mysteriously by a hidden nightmare... I am half awake and half asleep