NEWSLETTER

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Internationale Nachrichten

1. Indonesian prisons grapple with tuberculosis

Jakarta (dpa) - For months, Indonesian drugs convict Yohannes Ruli Karamoy watched his body wasting away, unaware that he had contracted tuberculosis. "I would wake up at night, sweating and coughing non-stop," 57-year-old Karamoy said as he waited to be examined by a doctor in a dimly lit clinic inside Jakarta's fortress-like Cipinang prison. "My chest felt heavy and I became very weak," he said in a faint voice from behind a surgical mask. The disease has left Karamoy frail and emaciated, weighing only 43 kilograms. His condition has improved since he began treatment in October, to the point where he can now walk two laps around the prison lawn.

Karamoy is far from alone in Indonesia in suffering from TB, a contagious bacterial infection that attacks the lungs. The nation of 250 million people had the second-largest number of TB cases last year, at 10 per cent of the global total, behind only India, according to the World Health Organization. An estimated 100,000 Indonesians in the general population die from TB each year, WHO statistics say, not including the many others who die after contracting HIV and TB. Official figures show the rate of TB deaths in prisons is roughly the same, at around 40 per 100,000 people. In 2015, at least 70 inmates out of a prison population of about 180,000 died from the disease. However, those fighting the spread of the infection in prisons believe these figures are significant underestimates. "TB detection is low in prisons in the regions," said Yulius Sumarli, a doctor at the Cipinang clinic. Many prisons do not have TB programmes in place at all, he said. "It's a challenge for prison authorities at the local level, given scant resources," he said. Severe overcrowding, a shortage of medical staff, and poor facilities are complicating government efforts to curb the disease. Indonesia's 477 prisons hold more than 181,000 inmates, even though they were designed for 118,000, according to the Justice Ministry. Overcrowding is worse in prisons in major cities. The Cipinang prison in the capital, designed for 1,100 people, now has 3,300 inmates. "That is why it is very important for us to detect as many cases as possible so they can be treated promptly and stop the disease from spreading further," Sumarli said.

The government's "war on drugs" has worsened overcrowding, with drug offenders like Karamoy accounting for about 80 per cent of inmates in many prisons, said Ummu Salamah, health chief at the country's correctional department. "We don't agree that drug users should spend time in prisons, because this has put a lot of pressure on our resources," Salamah said. "But the president has vowed to get tough on drugs, and the war on drugs sometimes contradicts rehabilitation policies," she said. Because many prisons lack isolation rooms, TB inmates often mix with healthy ones, said Yakub Gunawan, a programme manager at Red Institute, an organization which works with authorities to help inmates follow their TB and HIV/AIDS therapies. "Imagine if in a 12-square-metre room with 20 people there's one person with TB, how many people will get infected?" Gunawan said. A TB-positive person will stop infecting other people after two weeks of drug treatment, but many facilities in less-developed areas, mainly in eastern Indonesia, have no health staff at all. "In remote places, we have agreements with local government health offices to send nurses and doctors from community clinics

to prisons from time to time," Salamah said. On the Cipinang prison lawn, suspected TB cases arrive on a regular basis. Inmates wearing blue vests lined up in front of a table set up to register those who have TB symptoms.

"I've had a cough for about a week," said 24-year-old Abladi, who is awaiting trial for drugs possession, his mouth covered with a white mask. "Maybe it's just the flu," he said. TB patient Karamoy said he would be released from prison in two months, after serving more than four years, but he has to finish his course of treatment. "I want to be cured, so I'm making the best of my time here to get treatment because it's free," he said.

Source: DPA International, http://bit.ly/1UEWnOD (24.03.2016)

2. Bone TB is the prime cause for bone, spine deformities

With the rise in the number of people suffering from bone Tuberculosis in India, medical experts have said that the disease is one of the major reason behind bone and spine deformities. The ignorance about bone TB, during which the bacterium causing TB affects bones and the spine, also leads to limb shortening in growing children and full body paralysis. According to the medical statistics, 5-10 percent of the total TB patients in India suffer from bone TB and the figure was on rise. India witnesses 15 lakh TB patients every year. In India, Uttar Pradesh has the maximum number of bone TB cases followed by Maharashtra.

"Bone TB requires a different approach and duration of treatment is usually prolonged as compared to lung TB. About 50 percent of the bone TB affects spine, which causes paralysis if not treated well," said Abhay Nene, Spine Consultant at Mumbai based Wockhardt Hospitals. "The worst suffering are to live the life with a painful deformity, limb shortening in growing children. Young spine TB patients (growing age) can present with late onset paralysis years after their disease has healed. The loss of spinal cord function or permanent paralysis which doesn't recover is also not very rare in spinal TB patients."

According to the doctors, the disease starts growing over the cartilage and then extends to the underlying bone. "The symptoms include fever, chills, weight loss, and swelling. Bone TB is non infectious," Nene said. The doctors have also said that the bone TB causes damage to the bone marrow. Vispute, general physician at S.R.V. Hospital has said: "Bone TB may affect the bone marrow. After the drugs are given, the disease may live dormant in the bone marrow, causing it to affect the body's mechanisms of self renewal."

Source: Times of India, http://bit.ly/1pctxqR (11.03.2016)

3. Vietnam's Battle With Tuberculosis

HANOI, VIETNAM — Dr. Bui Xuan Hiep, the head of tuberculosis control in this city's Hoang Mai district, paged proudly through a large handwritten patient log."This district's cure rate averages 90 percent," he said. Still, Dr. Bui could see problems.

Seven patients had turned up with multidrug-resistant tuberculosis; four had been cured, two had died — and one had simply disappeared.

It's a story repeated throughout Vietnam. The nation was once racked by a tuberculosis epidemic, one of the worst in which H.I.V. was not the driving force. But officials fought back fiercely.

Twenty-five years ago, battered by the aftermath of a long war, chronic poverty and a heavy-handed government isolated from much of the world, Vietnam had nearly 600 cases of tuberculosis for every 100,000 residents. Today, it has less than 200. The country boasts a 90 percent cure rate for uncomplicated tuberculosis and cures 75 percent of its drug-resistant cases, easily beating the global average, 50 percent.

Indeed, public health officials worldwide have made remarkable progress against tuberculosis. Deaths from the disease have fallen drastically since 2000, according to the World Health Organization. Tuberculosis has been halted or reversed in 16 of the 22 countries that account for the vast majority of cases.

But Ban Ki-moon, secretary-general of the United Nations, last week warned that the fight was "only half won" and estimated that 1.5 million worldwide would die of the disease this year. There is no better example of how fragile this success may be than Vietnam. Hospital wards here are packed dangerously full, raising the risk that drug-resistant strains will spread.

The easy-to-reach patients have been treated, and many of the rest are the hardest to help: heroin-addicted couriers and laborers from the poppy fields of the nearby Golden Triangle, and mountain villagers who do not speak Vietnamese and are barely connected to the health care system.

But the biggest threat is that the money is close to running out.

"Our TB program is cost-effective and has great impact," said Dr. Nguyen Viet Nhung, its national director. "But I always emphasize that this is a preliminary success. We need to sustain it."

To reach Vietnam's ambitious goal of pushing prevalence rates down to 20 cases per 100,000 residents — essentially eliminating tuberculosis as a public health problem — its tuberculosis-control program needs to spend at least $66 million a year. It now spends about $26 million a year. About $19 million of that comes from foreign donors, with more than a third from the United States, Dr. Nguyen said. Evidence of donor help is everywhere.

The expensive diagnostic machines in hospital laboratories bear stickers from the United States Agency for International Development or from The Global Fund to Fight AIDS, Tuberculosis and Malaria, 30 percent of whose budget is paid by the United States. But The Global Fund, the chief support of the tuberculosis program here, is struggling and has promised support only through 2017. The White House, in its proposed budget for fiscal year 2016, reduced its contribution to the fund by 18 percent and to Usaid's tuberculosis programs by 19 percent.

Officials here and at the W.H.O. fear that hard-won progress may soon be reversed and a remarkable success story may come apart, with deadly consequences. After years in the shadow of the AIDS epidemic, tuberculosis is regaining its notoriety as one of the world's great killers: an airborne bacterium that spreads easily among people living crowded together — in jails, ships, mines, trenches or slums — and insinuates itself deep in the lungs and grows, slowly tearing apart the tissue until victims are coughing up blood.

Tuberculosis now kills more people around the world than AIDS, according to the W.H.O.: 4,100 a day, compared with 3,300 dying of AIDS, making tuberculosis the leading infectious cause of death in the world. Mortality from both diseases is dropping, but tuberculosis deaths have fallen more slowly, especially in Asia.

Vietnam's success where so many other nations have failed is not just because of donor money, said Dr. Mario C. Raviglione, the director of the W.H.O.'s global tuberculosis program. "It succeeds because it's a Communist country," he said. "Socialist countries put a lot of resources into primary care: lots of doctors, lots of clinics. And once central government adopts a thing, they really *do* it. They give orders." Tuberculosis is an ideal disease for a regimented treatment approach.

Almost all patients with "uncomplicated" tuberculosis — bacteria that are not drug-resistant — can be cured if they take a standard menu of four antibiotics every day for six months without fail.

In Vietnam, treatment standards set at the national level are followed by the entire public health network. The National Lung Disease Hospital in Hanoi oversees 64 provincial hospitals, which oversee 845 district hospitals, which oversee 11,065 neighborhood health clinics. The pharmaceutical-supply chain, the Achilles' heel in many tuberculosis-ridden countries, is impressive. On a weeklong tour of urban and rural clinics, not one nurse or patient reported ever running out of drugs.

Those neighborhood clinics — usually just a few examining rooms, a small pharmacy and a parking lot — are as ubiquitous here as police stations and firehouses in the United States. They treat many illnesses, but their role in tuberculosis is simple: Every tuberculosis patient in the district reports once a day to take his or her pills in front of a nurse. Each dose taken is checked off on a yellow card.

Most patients comply without complaint, doctors say. Many poor countries are chaotic; Vietnam, while poor, is not. Parks are neatly trimmed, public bathrooms are clean, and police in gold-buttoned uniforms and high-brimmed hats are omnipresent.

Nonetheless, there are a few stubborn patients — Dr. Bui's missing patient was a heroin addict who infected his mother with drug-resistant tuberculosis before disappearing. And the country has one surprising gap: It has no quarantine laws.

In New York City's outbreak of drug-resistant tuberculosis in the 1990s, officials legally locked up patients who refused to take their pills. The rare noncompliant patient here faces no such threat.

"We can't do that," said Dr. Le Minh Hoa, the head of treatment at Hanoi's provincial lung hospital. "And besides, we don't have enough spaces for the people who want treatment."

Patients with drug-resistant disease are especially hard to help. Their medicines, some of which are intravenous, must be taken for two years, and can cause deafness, psychosis and kidney failure. Patients must be hospitalized, their movements restricted to one or two corridors, sometimes for months until they are no longer coughing up live bacteria.

Hospital wards are full of stooped, forlorn-looking men and women in masks and pajamas waiting to be declared well enough to go home and become a district outpatient. If they become worse instead of better, the prognosis is usually grim. Extensively drug-resistant disease (XDR TB) requires even more toxic drugs costing 25 times as much. Most XDR TB patients here die.

Pham Thi Tuy, 25, was an unlucky woman — she caught a drug-resistant strain, perhaps at her job as a medical technician. Facing two years of treatment, she lay hooked up to an IV in Dr. Le's hospital, nauseated and exhausted by the drugs, watching videos on her cellphone all day. "I only went to the doctor for an earache," she said. "It didn't go away and didn't go away — and they finally did a test and said it was TB." She hoped her fiancé would wait two years for her to recover, she said — and then suddenly looked up at Dr. Le. "When I finish this, will I still be able to have children?" "Yes," Dr. Le said, patting her hand. Ms. Pham's eyes crinkled behind her mask, suggesting a sweet smile, and she gave a big thumbs-up.

There are many signs that the national tuberculosis program here survives on a shoestring budget. While its top laboratories have some modern equipment, the 64 provincial hospitals share only 60 rapid diagnostic machines, less than half the number they need, even though Vietnam pays only $17,000 for each, about a tenth of the American retail price.

More ominously, hospital wards are dangerously crowded. Seven patients a room, with beds only a foot apart, is not an uncommon sight. (That effectively means 14 inhabitants a room, as many patients have a relative sleeping on the floor or in a corridor to do nursing chores and bring food.)

Windows and doors are kept open to blow away the bacteria that patients cough up. In chilly Hanoi, patients like Ms. Pham wear parkas in bed; in tropical Ho Chi Minh City, the former Saigon, they perspire in the muggy heat.

Dr. Thuy Nguyen Thu, the head of the inpatient unit at the National Lung Disease Hospital, which treats the toughest cases, said four of her staff had caught tuberculosis in the last five years. New nurses were nervous, she said. Dr. Thuy had asked for ozone air filters, better fans and safer face masks, "but there are budget limitations."

Geography presents the tuberculosis-control program with another kind of obstacle. In the Shangri La-like valleys of Son La province, a six-hour drive west of Hanoi, some inhabitants live in villages with thatched roofs and speak only Hmong, Meo or Thai. Finding and keeping them in treatment is hard, said Dr. Tong Van Hieu, the director of the Quyet Thang neighborhood clinic in Son La. Some believe tuberculosis is caused by fog or dust or gold mine fumes, and turn first to folk remedies.

In the cities, a new problem is on the rise. Vietnam's growing prosperity lets some patients afford private doctors — who often ignore the official four-drug regimen and fail to insist their patients take every pill. Pharmacists sell antibiotics without prescriptions, so some wealthy patients swallow only what they feel like taking. As a result, Dr. Phat Nguyen Ngoc, the head of a district hospital in Ho Chi Minh City, said about a third of his patients with drug-resistant disease had gotten it because they had seen private doctors first and had taken too few pills, or the wrong ones.

And sometimes, even when compliant patients play by the rules, treatment fails, anyway.

In the Hanoi Lung Disease Hospital, Hoang Van Toan, a weathered farmer looking much older than his 49 years, sat wrapped in a blanket. He had taken all his pills, he said, but tuberculosis had

somehow outwitted them. The room was bare, with no television or any other diversion. “I talk to my wife,” he said, nodding at the woman sitting on the temporarily empty bed opposite him. “And I walk for three hours every day at dawn,” he added, pointing out the window to a nearby park. He wears a surgical mask as required, he said, but that makes no one nervous in Hanoi; thousands of passing motorcyclists wear them, too. What made him saddest, he said, is that it is still too dangerous for his grandchildren to visit. Asked if he would make it through the next two years, he said “Yes,” emphatically. “I was a soldier,” he added. “I fought the enemy. I can fight this.”
Source: NYT, http://nyti.ms/1WTBzjN (29.03.2016)

Forschung & Entwicklung

1. Simple test might predict who gets world’s deadliest infectious disease
What do Frédéric Chopin, Franz Kafka, and Nelson Mandela have in common? What sounds like a trivia question is at the heart of a long-standing mystery for infectious disease researchers. All three fell ill with tuberculosis (TB), which makes them an interesting minority. After all, only one in 10 people who are infected with the TB-causing bacterium *Mycobacterium tuberculosis* ever develops the disease. So what distinguishes those who get sick from those who don’t?
Now, scientists may have found one answer: a set of 16 genes that is more active in people who will develop TB in the next 1 or 2 years than in those who are infected but stay healthy. "It’s a real breakthrough," says Barry Bloom, a veteran of the fight against TB at the Harvard T. H. Chan School of Public Health in Boston who wasn't involved in the study. Knowing who will develop TB—and potentially spread it—could help target interventions, Bloom says; it could also make research on new therapeutics easier and cheaper.
More than 2 billion people—almost a third of the world's population—carry *M. tuberculosis*, and an estimated 1.5 million died from it in 2014, making TB the deadliest infectious disease in the world. But predicting who'll be unlucky enough to fall ill has so far been impossible.
To find a predictive signature, scientists took advantage of a large study of more than 6000 young people at risk of TB who were followed in South Africa for at least 2 years. The researchers compared blood samples from 37 people who developed TB and 77 others who carried *M. tuberculosis* but remained healthy; they discovered 16 genes that were more active in the former group. They then tested how well the signature held up in another nine participants who had developed TB and 30 who didn’t. The test confirmed the predictive power of the gene signature; another test in independent groups in Gambia and South Africa also validated the test, the team reports today in *The Lancet*.
The predictions are far from perfect. Overall, the gene signature picked out only about 80% of infected people who would go on to develop TB in the next 12 months, and it also wrongly fingered about one-third of the people who would remain healthy. And the longer before the disease developed, the less accurate the test became.
Still, "this is an exciting study,” says Helen Fletcher, director of the TB center at the London School of Hygiene & Tropical Medicine. Because people only become infectious after they have fallen ill, the research may provide a way to detect and treat TB before it can be spread from one person to another, she says. Bloom agrees; now, "there should be trials to establish whether those with the gene signature [predicting disease], if treated with anti-TB drugs, can be cured before developing active disease,” he says. (Because there are so many infected people and TB treatment consists of several drugs taken for up to 9 months, most people currently don't get treatment unless they get sick.)
Such trials are already being planned, says Willem Hanekom of the Bill & Melinda Gates Foundation in Seattle, Washington, one of the study's authors. “The signature does not have to be 100% specific and sensitive for interventions to work," he says. The current accuracy may be enough to start people on isoniazid, a drug given to prevent TB, Fletcher says, but not to give them full TB treatment,

which is associated with more side effects. The test kit itself needs a lot of work, too, she adds; it has to be made affordable and easy to use at any clinic.
The 16 genes include several well-known inflammation genes, suggesting that the signature may be an early sign that TB is developing. But there is more to it than just inflammation, Hanekom says. “There may be other things in the environment of these patients that trigger this signature long before TB disease," he says. "We just don’t know, but in terms of interventions it doesn’t really matter.“
The test could also be a boon for TB research, says Stefan Kaufmann of the Max Planck Institute of Infection Biology in Berlin, one of the authors. Testing therapeutic vaccines and other interventions is an expensive undertaking requiring huge study groups, he says. Including only people with the high-risk genetic signature could make the research much cheaper. “Even if you only have twice the number of people developing tuberculosis that you would normally have,” he says, “that is a big help.”
Source: Science, http://bit.ly/1RMJPR3 (30.03.2016)

2. 'Clogged-up' immune cells help explain smoking risk for TB
Smoking increases an individual's risk of developing tuberculosis (TB) - and makes the infection worse - because it causes vital immune cells to become clogged up, slowing their movement and impeding their ability to fight infection, according to new research published in the journal *Cell*.
TB is an infectious disease caused by *Mycobacterium tuberculosis* that primarily infects the lungs, but can also infect other organs. It is transmitted from person to person through the air. The disease can cause breathlessness, wasting, and eventual death. While treatments do exist, the drug regimen is one of the longest for any curable disease: a patient will typically need to take medication for six months.
For people exposed to TB, the biggest risk factor for infection is exposure to smoke, including active and passive cigarette smoking and smoke from burning fuels. This risk is even greater than co-infection with HIV. However, until now it has not been clear why smoke should increase this risk.
When TB enters the body, the first line of defence it encounters is a specialist immune cell known as a macrophage (Greek for 'big eater'). This cell engulfs the bacterium and tries to break it down. In many cases, the macrophage is successful and kills the bacterium, preventing TB infection, but in some cases TB manages not just to avoid destruction, but to use macrophages as 'taxi cabs' and get deep into the host, spreading the infection. TB's next step is to cause infected macrophages to form tightly-organised clusters known as tubercles, or granulomas. Once again here, the macrophages and bacteria fight a battle - if the macrophages lose, the bacteria use their advantage to spread from cell to cell within this structure.
An international team of researchers, led by the University of Cambridge, and the University of Washington, Seattle, studying genetic variants that increase susceptibility to TB in zebrafish - a 'see-through' animal model for studying the disease - identified a variant linked to 'lysosomal deficiency disorders'. The lysosome is a key component of macrophages responsible for destroying bacteria. This particular variant caused a deficiency in an enzyme known as cathepsin, which acts within the lysosome like scissors to 'chop up' bacteria; however, this would not necessarily explain why the macrophages could not destroy the bacteria, as many additional enzymes could take cathepsin's place.
The key, the researchers found, lay in a second property of the macrophage: housekeeping. As well as destroying bacteria, the macrophage also recycles unwanted material from within the body for reuse, and these lysosomal deficiency disorders were preventing this essential operation.
Professor Lalita Ramakrishnan from the Department of Medicine at the University of Cambridge, who led the research, explains: "Macrophages act a bit like vacuum cleaners, hoovering up debris and unwanted material within the body, including the billions of cells that die each day as part of natural turnover. But the defective macrophages are unable to recycle this debris and get clogged up, growing bigger and fatter and less able to move around and clear up other material.

"This can become a problem in TB because once the TB granuloma forms, the host's best bet is to send in more macrophages at a slow steady pace to help the already infected macrophages."
"When these distended macrophages can't move into the TB granuloma," adds co-author Steven Levitte from the University of Washington, "the infected macrophages that are already in there burst, leaving a 'soup' in which the bacteria can grow and spread further, making the infection worse."
The researchers looked at whether the effect seen in the lysosomal deficiency disorders, where the clogged-up macrophage could no longer perform its work, would also be observed if the lysosome became clogged up with non-biological material. By 'infecting' the zebrafish with microscopic plastic beads, they were able to replicate this effect. "We saw that accumulation of material inside of macrophages by many different means, both genetic and acquired, led the same result: macrophages that could not respond to infection," explains co-author Russell Berg.
This discovery then led the team to see whether the same phenomenon occurred in humans. Working with Professor Joe Keane and his colleagues from Trinity College Dublin, the researchers were able to show that the macrophages of smokers were similarly clogged up with smoke particles, helping explain why people exposed to smoke were at a greater risk of TB infection.
"Macrophages are our best shot at getting rid of TB, so if they are slowed down by smoke particles, their ability to fight infection is going to be greatly reduced," says Professor Keane. "We know that exposure to cigarette smoke or smoke from burning wood and coal, for example, are major risk factors for developing TB, and our finding helps explain why this is the case. The good news is that stopping smoking reduces the risk - it allows the impaired macrophages to die away and be replaced by new, agile cells."
Source: Medical Xpress, http://bit.ly/1WZRe0L (25.03.2016)

3. Phase 1 Clinical Trial of TB Drug Candidate TBA-354 Discontinued
NEW YORK, NY (March 11, 2016)—TB Alliance has announced that it has stopped the clinical development program for the tuberculosis (TB) drug candidate TBA-354. This follows the voluntary hold it placed on the Multiple Ascending Dose (MAD) Phase 1 study of TBA-354 in January 2016.
The MAD study, designed to test the tolerability and pharmacokinetics of ascending doses of TBA-354 in healthy volunteers, resulted in side effects in the initial cohort. Based on the observed side effects and pharmacokinetic data of TBA-354 generated in this cohort, TB Alliance together with its scientific advisors made the decision to stop the clinical trial and the clinical development program of TBA-354.
“Observed toxicity was generally mild and all subjects have fully recovered, but the probability of this drug successfully advancing to the stage where it could become a component of a safe and effective novel regimen that would have a major impact on the global TB problem is too low to justify continued investment,” said Carl Mendel, MD, Senior Vice President, Research & Development, TB Alliance. TBA-354 is a member of the nitroimidazole class of compounds. The Phase 1 program, which included a successful Single Ascending Dose study as well as the MAD study, was initiated in February 2015 and was halted in January 2016. TBA-354 was the first new TB drug candidate to move into Phase 1 since 2009, and its discontinuation underscores the dearth of early-stage clinical TB drug candidates in the pipeline.
“The results of the Phase 1 TBA-354 trial remind us that attrition and risk are inherent to research and development, and therefore it’s important to constantly replenish the reservoir of new drug candidates advancing into the global pipeline,” said Dr. Spigelman. “Today, we need to drive investment in TB drug research to dramatically increase the number of candidates entering clinical development.”
Tuberculosis is the world’s leading infectious disease cause of death, taking the lives of 1.5 million people each year. Shorter, simpler, and improved treatments are critical to achieving TB control and stopping the global pandemic.
Source: TB Alliance, http://bit.ly/1VwpT7R (15.03.2016)

Reportage

1. 139 Days of Isolation: What It's Like Living With Tuberculosis

On Thursday, April 25th, 2013 I was informed that I had tested positive for Multi-Drug Resistant Tuberculosis (MDR TB), an infectious deadly lung disease that kills approximately 1.5 million people every year (Center for Disease Control and Prevention). The death rates in some countries around the world are staggering. This is sometimes difficult to process but I try to remind myself that I am no better and that I am no more deserving of life than those who die from the disease. I am extremely privileged and lucky to say that I did not have to be concerned about death because of my extraordinary access to health care. I understand in many ways life itself can be a privilege.

Prior to diagnosis, I had been experiencing chest pain, shortness of breath, a sore throat and fatigue but the side effects from the medication were much more harsh and challenging. With treatment consisting of such a rigorous regimen of many drugs, I've experienced an unpleasant variety of side effects from nausea, fatigue, restlessness, anxiety, loss of hearing, temporary impairment of vision, peripheral neuropathy in my feet, and loss of appetite. I'm pleased to say that most of these issues have subsided.

I remained in isolation for 139 days over the summer of 2013. I was able to spend time with family and friends during this time if I was outside. TB is a communicable disease but there are many misconceptions about TB because of the lack of education and awareness in our culture (Center for Disease Control and Prevention). With the movement of free flowing air and by keeping a healthy distance/wearing a mask, it was safe to do so. TB is a difficult disease to overcome because of the stigma that exists. I imagine there are many people who feel extremely isolated and fear how they will be perceived by others if they share about their illness. There are people who don't feel they have the necessary support to continue the rigorous treatment. To TB patients, I share my story in the effort to let you know that you are strong and resilient. If you ever need someone to chat with, please email me at tenzinkunor@gmail.com. It would be my pleasure to support you in your recovery. Disease is part of the human condition. Always has been and always will be. I think it's important to understand that the enemy is the disease. Not the person who is the victim of it. I think it's extremely dehumanizing and deplorable how we treat people with certain diseases.

Although, my father and brother both had MDR-TB, I haven't heard too many patient/survivor stories about TB. Last month when I attended a survivor training session at the National TB Conference, I had the wonderful opportunity to connect with fourteen other TB survivors which was super fascinating. After hearing stories from survivors, there were multiple themes that surfaced. One thing I've given some more thought is the mental health and wellness of TB patients. It certainly appears that many TB patients suffer from anxiety and depression. Although, medication can be partially responsible for it, isolation is most definitely another contributor. Not feeling connected to others and the rest of the world can be damaging to one's health and wellbeing. In addition to these two contributors, the stigma that surrounds TB, infectious disease, and other illnesses also creates challenges. It can be extremely dehumanizing to feel the stigmatization of your lived experiences and that your literal breath is unwelcomed and deemed harmful to others. The thing that makes you most human and alive - your breath - is not desired in this world. A poem by the brilliant Nayyirah Waheed makes me think more about that, "a friend. is someone who supports your breath." About how my support system, that consisted of family and friends, were always the ones who supported my breath. And made me feel alive. Always.

Every time I reflect on my experience with TB I, without hesitation, think about the wonderful people in my life and feel a great sense of gratitude. My loved ones have relentlessly supported me and have always, always tried to shield and comfort me from struggle and suffering. I am truly grateful for that. TB has made me a more grateful and gracious person. And I honestly think TB has also made me a better person in many ways (I know this comes from an extremely privileged set of circumstances).

At the same time, I don't want the stigma to limit the importance and significance this illness has had in on my life and my identity.
Moving forward, let's share our stories. It is from there we begin to liberate ourselves and envision a better, more social just world - one that is worth tirelessly fighting for. Let's advocate for better diagnostics, treatment, and prevention, and let's do this all while considering how harmful stigmatization of TB, other illnesses, and disabilities can be. The stigma that exists surrounding TB is the key component in the illnesses' failure to foster a community of patients/survivors. While TB has become the leading infectious killer and takes approximately 4,400 lives daily (Center for Disease Control and Prevention), there fails to exist a strong and sustainable movement that organizes people to take action and advocate for our communities, and for a better world. That can certainly change. The arduous work that many survivors and organizations are doing makes me believe. And I feel good about that.
Source: Huffington Post, http://huff.to/1ReXnSX (22.03.2016)

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