



# **iGEM IIT Roorkee**

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## **Patient Interview**



## Interview with Patient turned Survivor

### Ms. Khushboo Gupta, MDR-TB Survivor

**Khushboo Gupta**, a 25-year-old, talked about how she contracted tuberculosis and her journey throughout the treatment.

**Q.1 Please tell us about the disease you were suffering from? And for how long?**

**A.1** In 2015, I was a third-year undergraduate student. During that time, I developed a lump near my breasts, and it started getting bigger with 'puss' inside it. After a few medical tests in Delhi, I was diagnosed with **Extrapulmonary tuberculosis**, in which my lymph nodes got swelled up. Additionally, TB infection bacteria was resistant to **rifampicin**. The **GeneXpert test** was used to diagnose TB, and doctors removed the puss via an injection.

**Q.2 What were the symptoms that led you to a hospital for consulting a doctor?**

**A.2** In the beginning, I had absolutely no reason to visit any doctor. But, then after a year or so (approximately in 2016), I started feeling nauseous and hypersomniac. There was a time whenever I brushed my hair with a comb; there used to be hair all over. Then I started losing weight as well. All these symptoms landed me in a hospital. Also, there were no side effects during the first three months of medications, but I wasn't getting well.

Despite this, the swelling on lymph nodes was not reducing. We (my family and I) then went to a chest physician who examined me and told me to undergo a biopsy. He told me to send the samples for testing, including a GeneXpert TB test. Two days after my biopsy reports came back positive for multidrug-resistant TB (MDR-TB), high resistance to rifampicin [TB drug].

### **Q.3 Did you face any difficulties during the diagnosis procedure?**

**A.3** After the initial diagnosis, my doctor prescribed me an **antibiotic course** of 5 months. I had to take 'Streptomycin' injections every day. I remember how hard it was, and literally, I used to cry while receiving the painful injections daily, which I took for eight months [not only this, but it required daily visits to the healthcare center, disrupting normal life]. But I feel proud of myself that I managed to complete that course of injectables without missing even a single dosage. The lump was under control after the course was complete, meaning it wasn't growing but still wasn't reducing in size.

It was hard to keep up with all the medicines for very long, but now I'm doing very well. Sometimes I even forget that I have survived to be sick for such a long time.

**Q.4 What kind of mistakes did you make during your medication?**

**A.4** I specifically remember one mistake I made, which delayed the time of recovery for me. So, I used to take the TB medication on time, but I didn't care about the diet I was taking. All the bitter taste of medicines and nausea killed my appetite. Since antibiotics require a very proper and healthy diet (for example, a diet consisting of 5–6 egg whites a day), the doctor told me to check on the food I had been consuming during the treatment. I overlooked it and got myself back on track with a balanced diet containing protein-rich food.

**Q.5 Did you get better results after your treatment? What was the medication strategy your doctor followed for the treatment after the results?**

**A.5** No. I did not feel better and had to get a second biopsy. When I again had my GeneXpert testing back in 2016 and was diagnosed to be resistant to rifampicin, the doctor prescribed a second-line MDR-TB treatment regimen (second-line drugs are used to treat a disease that is resistant to standard first-line treatments). He told me I have to take daily injections for at least six months. (Treatment also requires taking many different pills for up to two years). I felt disappointed at that time for not being able to get better.

**Q.6 How were the hospital facilities? (Like the staff was supportive, did hospitals have proper protocols for patient care, so on and so forth.)**

**A.6** I was admitted to the All India Institute of Medical Sciences (AIIMS). I must say that even after being the country's one of the best hospitals, the admin facilities, and patient's satisfaction were compromised to some extent. In my opinion, still, the main challenges confronting the public hospitals today are deficient workforce, unmanageable patient load, and high out-of-the-pocket expenditure. Though the medical staff was supportive, the admin facilities were the main problems, as I remember standing in a queue for 2-3 long hours. Lastly, the doctors were highly competent, and they treated the disease I had, good.

**Q.7 Tell us more about the emotional, economical and psychological impact you had gone through?**

**A.7** I had a significant impact on my psychological as well as emotional health. Initially, things were fine, but during the 2nd year, I felt dizzy and nauseated the whole day due to the immense amount of antibiotics I took. It also took a toll on my mental health as I had suicidal thoughts and later diagnosed with mild depression. I even started to lose the memory of fundamental things, which was just a phase and got over with time and effort.

**Q.8 What was your work and home environment like before and after the diagnosis of MDR Tuberculosis? What advice would you give someone who suspects they have TB?**

**A.8** So, before the diagnosis, I had a sorted life of a young college girl who used to hang out with her friends and family. Once things started to turn around, I got a little bit conscious about myself, always thinking about why'd it happen and what people will think of me, etc. etc. Then, when I was diagnosed for the second time, I was working in an MNC. There, I didn't tell people about my condition due to the fear of being judged (for no reason whatsoever), though I knew that my disease wasn't communicable. I had that constant thought running through my head that no one would be friends with me or talk even. So, I decided to get myself treated and get better as soon as possible with all of my strength.

My advice for someone skeptical about contracting TB would be that MDR-TB is curable if you religiously follow your medication regime and do not miss any doses. It is essential to stop taking TB medicine only when a specialist or nurse tells you to do so. This is because if you do not accept all the TB medicine, or if you stop taking it too early, there is a chance that the TB could come back; it would be more challenging to treat its second time around. So, be safe and be responsible for yourself.

**Q.9 What message would you give other patients or the general public in regard to the problem of Antimicrobial Resistance?**

**A.9** As a young career-oriented person, it is so difficult to accept a situation like this. But I am so lucky that I have huge family support from my mom, dad, and sister. They gave me confidence that whatever will happen, they will always be there for me, which also gives me a lot of strength, and I am pleased today to be free of the disease and completely cured with my family supporting me at all times.

I wish for people who are suffering from drug-resistant TB to be diagnosed in a timely manner. To be afraid is understandable but to be negligent is what causes the actual problem. I would advise consulting a doctor before it's too late and be strong at all times. Maintain positivity around you for keeping up your hopes. Also, I believe new medicines are required for larger numbers of patients with drug-resistant tuberculosis. Only then will we achieve our TB-free target in India by 2030. Lastly, I would say, "Precaution is always better than cure," so be safe and live a full, happy life.

**The interview was an incredible eye-opener on understanding a patient's story and the emotional, psychological, and physical conditions they had to go through. Team iGEM IIT Roorkee respects and salutes all the MDR infection patients for their courage, especially Ms. Khushboo Gupta, for taking some time out to enlighten us with her story.**