### Robert David (Haiti)

In 1986, when Robert David was 19, he complained of cough, night sweats, and fever. Initially he used herbal remedies to try to get better, but Robert went to hospital when his conditioned worsened and he lost weight and experienced shortness of breath. There, he was diagnosed with tuberculosis and prescribed two medications to take. In order to receive this treatment Robert had to commute for two hours from his home to the hospital, and often had to wait at the hospital for hours before being seen by a doctor.

In 1987 Robert was able to switch to a clinic closer to his home. He was prescribed three anti-TB drugs (isoniazid, ethambutol, streptomycin) for an 18 month period. It was very difficult for Robert to acquire his medications because of their cost; his family sold half of their land in order to pay for the drugs. Robert stopped this treatment in 1988, but continued to be sick.

In 1990 Robert was treated in a sanatorium for six months in Port-au-Prince, where he took the medications isoniazid, ethambutol, pyrzinamide, and rifampin. After six months he was released and told to continue this treatment for 8 more months, then to take isoniazid and ethambutol for two more months. Ultimately, Robert was unable to acquire many of his medications because of political instability in the country. His symptoms persisted, and in 1992 he was readmitted to a sanatorium and treated with thiazina. His treatment was inconsistent, though, because political upheaval meant that medications were often not available.

In 1993 Robert went to the Clinique Bon Sauveur reporting chronic cough, night sweats, and weight loss – he weighed 110 lbs. Robert was prescribed multiple TB drugs. He complained of buzzing in his ears and nausea, but was very motivated to continue his treatments. A sputum sample was collected in summer 1994 and tested for drugsensitivity. The test showed that Robert's TB was resistant to 5 of the main TB drugs. The drugs that would work against his TB were not available in Haiti and had to be specially imported by the clinic. Once Robert was on these drugs his condition improved greatly – he gained weight and was able to breathe more deeply. Improvement was short lived, though, and soon his condition began to deteriorate once again. Robert died in December 1995.

Case study summarized from Paul Farmer, "Social Scientists and the New Tuberculosis," pp. 174-194 in <u>Partner to the Poor</u>, ed. Haun Saussy (Berkeley: University of California Press, 2010).

- 1. What signs and symptoms of TB did Robert express?
- 2. What treatments did Robert receive for his TB?
- 3. What difficulties did Robert face obtaining treatment for his TB?
- 4. What side-effects did Robert experience from TB medications?

### Blanca (Peru)

Blanca first thought she might be sick with tuberculosis when she began coughing in 1995, but did not seek out treatment because she afraid to find out the truth. She lived with her husband in the home of her mother with six of her siblings. Four of her siblings had already been diagnosed with TB.

Blanca was diagnosed with tuberculosis at age 22 after a sputum sample tested positive for the tuberculosis bacillus. Even though her siblings, from whom she had likely contracted the disease, had been shown to have drug resistant TB, Blanca was prescribed the standard six-month treatment regime of four TB drugs. After one month of treatment, instead of improving Blanca's x-rays showed that her condition was worsening. Local health workers took a sputum sample and sent it to be tested for drug-susceptibility. Tests revealed that her TB was resistant to isoniazid and rifampin, the two most powerful TB drugs. Despite this, Blanca was told by health authorities that she needed to complete her prescribed course of treatment, even though at this point the prescription was to take the two drugs to which she had been shown to be resistant! Unsurprisingly, Blanca's condition continued to deteriorate and when she finished her course of treatment she was experiencing fevers, coughing up blood, and weighed only 80 lbs.

At this time, Blanca was prescribed a range of second-line TB drugs that her TB should have been susceptible to. These drugs were not included in the public health program, though, which meant that Blanca had to pay for them herself – a cost of \$200 a month. Despite her entire family pooling their resources, they were only able to come up with enough money to pay for one week's worth of medication! Blanca knew that it would be impossible to continue the treatment for the months that were prescribed.

Several months later, Blanca finally received the necessary medications from the community health organization, Socios en Salud. Soon, test showed that TB bacteria were no longer present in Blanca's sputum – she was getting better! But, after being treated with inappropriate medications for so long, Blanca's TB was now resistant to five drugs instead of the initial two.

Case study summarized from Paul Farmer, <u>Infections and Inequalities</u>, pp. 235-240 (Berkeley: University of California Press, 1999).

- 1. What methods did health workers use to identify Blanca's illness?
- 2. Why did Blanca not get better when she was first treated for TB?
- 3. What challenges did Blanca face to receiving the appropriate TB medications?
- 4. What could the health care system have done differently to minimize the development of Blanca's drug-resistance?

### Jean Joseph (Haiti)

When Jean first started to cough, he tried to get better by drinking herbal teas. When his cough only got worse, he decided to go to a TB hospital in Port-au-Prince because he knew they had x-ray machines there. Test results showed that Jean did have TB, and he was prescribed four anti-TB drugs.

Jean did not get better. He kept coughing. After he coughed up blood, a specialist referred Jean to a sanatorium where he was treated for three months. Even though he took the prescribed medication under the Directly Observed Therapy program Jean did not improve. After he had taken the medications for over a year and not gotten any better, Jean stopped taking the drugs and went to a herbal doctor. This did not work either, and Jean reentered the sanatorium shortly afterwards.

Jean was told that he would need to take different drugs that would work better on his drug-resistant TB. In order to pay for these more expensive drugs, Jean's family began to sell their furniture, farm animals, and land. Jean improved on these drugs and was able to return home. After five months of treatment, though, Jean's family could no longer afford to buy the necessary medications. After stopping the treatment Jean's TB returned.

Soon his three sisters and brother were also coughing. They were given the normal treatment for TB but did not improve. A nurse, suspecting that Jean and his siblings had drug-resistant TB, sent a sputum sample away for drug-susceptibility testing but Jean was never given the results of the test.

One day Jean heard about another TB clinic where drug-resistant patients were being treated. He brought his family to the clinic to be treated. After all being placed on the correct regimen of medications for drug-resistant TB, the whole Joseph family tested negative for TB.

Case study summarized from Paul Farmer, "The social impact of multi-drug-resistant tuberculosis: Haiti and Peru," in The Return of the White Plague, pp. 163-177 (New York: Verso, 2003).

- 1. How did health workers figure out that Jean had TB?
- 2. What treatments did Jean try in order to get better?
- 3. What challenges did Jean face to receiving medication for his drug-resistant TB?
- 4. Why do you think Jean might have tried herbal remedies to get better?

### Corina Bayona (Peru)

Corina lived with her husband, son, daughter-in-law, and grandchild in a one-bedroom house in a slum north of Lima. When Corina started coughing she tried herbal remedies to cure herself because the closest medical clinic was closed by the time Corina had returned home from work. When her cough got worse she finally saw a doctor. He took a sputum sample that showed an active TB infection. Corina began the standard TB therapy of four anti-TB drugs and seemed to get better.

Corina began coughing again. She did not want people to know she was sick because of the stigma of having TB, so she started receiving treatment from a private clinic. This cost a lot more than public treatment, though, and soon Corina could only afford to buy two of the four medications she was prescribed. Corina kept getting sicker and had to stop working.

Now, Corina no longer responded to the standard medications used to treat TB. A doctor recommended that she go into a hospital. Corina went to a private university teaching hospital, but she was unable to pay for supplies. She then went to the public hospital, where Corina was told that she had to supply her own syringes, gloves, and gauze. Then, hospital workers went on strike and Corina was unable to receive any treatment at all. When the strike ended and she went back to the hospital to receive her medications, a doctor rudely told her that it was her fault that she had completed her treatment and he sent to her another hospital in her neighbourhood. A doctor there was also unwelcoming and told Corina to go back to her local health care clinic.

Corina returned home and suffered from TB for three years. She sought help again after coughing up blood. Test results now showed that she had drug-resistant TB; yet, the doctors prescribed her the drugs to which she had just been shown to be resistant!

Eventually Corina heard about drugs that would work on drug-resistant TB. It would cost 500 soles a month to pay for these drugs, and the family was unable to produce this amount of money. When a community-organization was finally able to provide the medicines to Corina for free, it turned out that she had a bad-reaction to them and was unable to take them. Corina died of her tuberculosis.

Case study summarized from Paul Farmer, "The Consumption of the Poor," in Partner to the Poor, ed. Haun Saussy, pp. 222-247 (Berkeley: University of California Press, 2010).

- 1. How did the stigma of having TB affect Corina and her treatment?
- 2. Why do you think Corina developed drug-resistant TB?
- 3. What problems can you see with the care that Corina received?